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ABSTRACT

Presented are papers from a 2 day conference in 1972 on screening and assessment of high risk children, 0 to 5 years of age, to detect developmental disabilities in physical, cognitive/intellectual, socio/emotional, and language areas. Briefly reviewed are legislation, reports, and programs which have concerned children's development in the last decade. Two papers consider physical screening and assessment; one paper focuses on screening devices such as the Rapid Checklist; the other paper indicates preference for use of medical histories, developmental screening tests, and eye screening tests. Presented in one of two papers on cognitive/intellectual screening is a procedure for measuring heart rate and electroencephalographic responses of newborns to stimulation to evaluate children's neurological functioning, and focused upon in the other paper are limitations of infant mental tests. Discussed in relation to screening in the socio/emotional area are approaches to using observational information for assessment purposes, and ethical problems encountered in design of measures and implementation of mass screening, respectively. Considered in the first of two papers on screening in the language area are issues and problems such as the primitive nature of assessment technique instruments; stressed in the other paper is the difficulty of screening for hearing ability. Recommendations of the conference include the need for an improved confidential system to compile data on each child's tests and development. Touched upon in the summary of the conference's proceedings are such points as insufficient manpower for mass screening and expense. (MC)

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Background PAPERS of the Boston Conference · October 19-21, 1972

Screening and Assessment of Young Children at Developmental Risk

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

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Background
PAPERS of the
Boston Conference, October 19-21, 1972

Screening and Assessment of Young Children at Developmental Risk

President's Committee on Mental Retardation

Washington, D.C. 20201

DHEW Publication No. (OS) 73-91

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acknowledgements

The minor editing, organization, and publication of these background papers were made possible by Contract HEW-OS-72-160 from the President's Committee on Mental Retardation to the Association of University Affiliated Facilities. The contract called for the planning and management of a conference on the early screening and assessment of children. The AUAF principal investigator solicited and subsequently edited and organized these tape-recorded presentations given at the conference, which was held in Boston, Massachusetts in October, 1972. Each presenter graciously reviewed and further edited the tapescripts for inclusion in this publication. Although in some cases the presenters/debaters mention in their text that they are assuming a largely affirmative or negative position, it should be understood that regardless of their personal convictions, all were asked to take one or the other position for the sake of maximally broadening the perspective of the interdisciplinary participants at the outset of the conference. Since several of the participants were uncomfortable being purely affirmative or negative and since the format was not one of formal debate, some of both the pros and cons for early screening can be detected in most of the presentations, thus the label quasi-debates. The Conference Schedule is included herein to give the reader a better sense of context; the companion State-of-the-Art Monograph is available from the Superintendent of Documents, Government Printing Office, Washington, D.C. 20402.

The Boston screening conference represented the combined efforts of many agencies of the Department of Health, Education, and Welfare and numerous individuals who were concerned with the needs of children at risk of being developmentally delayed. Mrs. Jeannette Rockefeller, a co-chairperson of the conference, led the PCMR work group which, for more than two years, pursued the topic of the specific needs of young children. She was joined before and during the conference by Dr. Julius Richmond who shared the conference chair with her. Technical and financial assistance were provided by the National Institute of Child Health and Human Development, Office of Child Development, Health Services and Mental Health Administration, and the Social and Rehabilitation Service. Without them, neither the conference nor this publication would have materialized. Other credits are given in the Introductory and Closing presentations of this publication.

The staff of PCMR, under the original direction of the now retired Executive Director, Dr. Joseph Douglass, and later under the direction of the Acting Executive Director, Mr. Fred Krause, with the assistance of Mr. Ray Nathan on public information and Messrs. Stanley Phillips and Tadashi Mayeda, as government and consulting project officers, all, in some way, contributed to the success of the conference and the production of these proceedings. The secretarial assistance of Ms. Opal Every and the arts and graphics work of Mr. William Borthick are also gratefully acknowledged.

John H. Meier, Ph.D.
AUAF Principal Investigator

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program

SCHEDULE

THURSDAY
October 19, 1972

7:00 - 9:00 P.M.

RECEPTION

HOTEL RITZ-CARLTON

Downtown Boston

FRIDAY
October 20, 1972

9:00-9:30 A.M.

GENERAL SESSION
Jimmy Fund Auditorium
THE CHILDREN'S HOSPITAL MEDICAL CENTER

Welcome, Introduction and Conference Overview:
MRS. ROCKEFELLER and DR. RICHMOND

9:30-12:00 Noon

Debate about the following: PHYSICAL, SOCIO/EMOTIONAL, COGNITIVE/INTELLECTUAL, AND LANGUAGE FACTORS ON THE SCREENING AND ASSESSMENT OF YOUNG CHILDREN Pros and cons presented by eight experts on the young child's health, behavior, feelings, thoughts, language and environment.

12 Noon - 1:30 P.M.
LUNCH/FREE TIME

1:30 P.M. WORK SESSION I

Small group discussions on assigned topics (Group determined by color coded name tag)

2:30 P.M. WORK SESSION II

Small group discussions new round of topics recommendations

3:30 P.M. PLENARY SESSION
Jimmy Fund Auditorium

4:00 P.M. ADJOURN
No host evening

SATURDAY
October 21, 1972

9:00-10:30 A.M.

WORK SESSION III

Small group planning on implementation strategies

10:30-11:00 A.M.
Break

11:00-12:00 Noon

WORK SESSION IV

Small group summaries and recommendations

12 Noon - 1:30 P.M.
LUNCH/FREE TIME

1:30 P.M.

GENERAL SESSION
Byers Room

Sharing of recommendations

3:00 P.M.

CONFERENCE SUMMARY

4:00 P.M. ADJOURN

introduction

Mrs. Jeannette Rockefeller
President's Committee on Mental Retardation
Washington, D.C.

A decade ago, several distinguished leaders and scholars, many of whom are attending this conference, became alarmed that in America there are many citizens who carry a heavy social or environmental burden and that our ability as a society to care for them has been extremely limited. Ten years later, even though we know the disaster that neglect can have on a young child, we are faced with exactly the same problems as those gentlemen saw ten years ago. Now, through the good graces of federal agencies, we see the problem of the unattended infant and young child as one of the most serious that we have today. Five have combined their efforts to bring you here today. I hope that this marks the start of a coalition to bring the needs of the young child to the attention of the many clinics, agencies, and organizations in our young country trying to serve children. Perhaps your good efforts will result in establishing priorities under which children who most need services will be led into the meager system that we now have.

On behalf of the President's Committee on Mental Retardation, I would like to thank Dr. Vernon Wilson, the Administrator of the Health Services and Mental Health Administration for helping us in this effort. Thanks are also due to Dr. Edward Zigler, the former Director of the Offices of Child Development, and to its Acting Director, Mr. Saul Rosoff; to Dr. Gerald LaVeck, the Director of the National Institute of Child Health and Human Development; and to Mr. John Twiname, the Administrator of the Social Rehabilitation Service.

May I also take this opportunity to introduce to you some of the committee members of the President's Committee on Mental Retardation: Mrs. Louise Ravenel, Mr. Ralph Ferrara, Mr. Kenneth Robinson, and Dr. Beth Stephens, and our extremely capable Executive Director, Mr. Fred Krause. All of us welcome you to this conference and bid you good luck in the venture. And now may I please introduce someone who really does not need any introduction, I think all of you have known him one way or another in many of his roles and guises... Dr. Julius Richmond.

Julius Richmond, M.D.
Harvard School of Public Health
Cambridge, Massachusetts

I want to express my appreciation to Mrs. Jeannette Rockefeller for all her work in the co-chairmanship and in the planning of this conference. All of us who encountered her in our work on behalf of the mentally retarded, in the field of mental health, and in the field of health generally, know the resourcefulness she brings to this work; and this occasion is no exception. I would like also to express my appreciation to Dr. John Meier for the very considerable work he has done in the planning for this conference, and to

Dr. Allen Crocker and his very able staff, who have been in charge of our local arrangements. We are deeply indebted to them.

I want also to express the pleasure of the staffs of the Children's Hospital Medical Center and the Harvard Medical School in having all of you here. We hope that while you are here you will take advantage of the opportunity to visit laboratories and talk to people in various programs here that you may find of interest.

It might be well for me to make a few comments, building on Mrs. Rockefeller's remarks, concerning the historical setting in which this conference is taking place. I would like to suggest that this conference is unique, not only in terms of its content, but also historically, in terms of its timing. As Mrs. Rockefeller has indicated, perhaps we have not done as much as we should in the decade since the report of the President's Panel on Mental Retardation in 1962; but we have gained a great deal of knowledge and experience, and I think that we are here to assess our knowledge and experience, and in the light of it to look at where we should be moving. As James Thurber once quipped, "It's better to know some of the questions than all of the answers."

We have a rich history on which to build, but I do not want to look back over the centuries of childhood. Philippe Ariès did that very well in his book Centuries of Childhood[1]. I would, however, like to look a little more closely at the last decade, starting with the President's Panel on Mental Retardation, appointed in 1961, which set in motion the establishment of the President's Committee on Mental Retardation, under whose auspices we are meeting today. In addition we meet with the support, as Mrs. Rockefeller indicated, of the various related Federal agencies. I think it is important to acknowledge that that committee has continued to try to develop the theme of the report of the President's Panel on Mental Retardation, and that it has been trying to do this by cutting across disciplines, and particularly at the Federal level by trying to cut across agencies. The support for this conference is clear indication that it is feasible to do this. Not only did the President's Committee on Mental Retardation evolve as a consequence of the report of the President's Panel on Mental Retardation, but in part as a consequence of that report, in part because of the Zeitgeist--the growing concern about the interests of children, child development, and all of human development--we saw in 1962 the establishment of the National Institute of Child Health and Human Development, which has given considerable impetus to the development of research in this field. Perhaps we in the child development establishment have been too timid in lobbying for support of the National Institute in order to gain for it more resources with which it could develop research programs.

But also as a consequence of the President's Panel on Mental Retardation and the Zeitgeist of the early 1960's, we had in 1963 some very important legislation--the Mental Health and Mental Retardation Act, a landmark in many

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[1]Philippe Ariès, Centuries of Childhood: A Social History of Family Life, translated from the French by Robert Baldick (New York: Alfred A. Knopf, 1962).

ways, but especially because of its focus on developing services for a defined population and on the development of the comprehensive community mental health services through the setting up of a network of community mental health centers. I think that the concept of services for a defined population is an exciting concept, which we have yet to implement fully; I predict that the consumer movement will push us rapidly in this direction if we as professionals do not move more rapidly to implement this delivery system--particularly in the delivery of comprehensive health services for young children.

It is appropriate that we look at some of the limitations of the comprehensive community mental health center programs. Not only has there been some failure of programs to serve the total population in a catchment area. Also we should note that there is a tendency for the interests of children to drop low in the priorities in most of the community mental health center programs. As a consequence this year ten million dollars were earmarked specifically for children. And that is all too little and, unfortunately, all too late. But the conceptual approach of serving defined populations in a systematic and comprehensive way remains an exciting one, and certainly an objective toward which we should continue to strive for all health services--not only mental health services.

We have, then, the drift in the early sixties toward certain kinds of categorical health programs, and by the mid-sixties--perhaps as a consequence of the civil rights revolution and the antipoverty efforts that stemmed from it--the growing concerns about the distribution of health services, which later came to be defined more clearly as a crisis in health care. Consumers across the country began to express their interest in more and better health services; and by the mid-sixties we were in the midst of a consumer revolution in the field of health. In 1965, in that one year, we had passed Titles 18 and 19 of the Social Security Act--Medicare and Medicaid--the Regional Medical Programs; Comprehensive Health Planning; the Maternity and Infant Care Programs of the Maternal and Child Health Services Division of the Health Services and Mental Health Administration; the Children and Youth Programs; and in late 1964 and 1965, the Office of Economic Opportunity programs, which included comprehensive approaches to child development through Head Start and a comprehensive approach to health care through the development of the Neighborhood Health Centers. If we regard the health care system as a "nonsystem," and if we look at it in terms of its chaos and fragmentation, it is because that is indeed the way it is. We are still trying to digest the programs that were generated through this bumper crop of legislation.

Consumer pressures began to mount for the implementation of this legislation more adequately. This pressure was manifested in 1967 by the passage of the amendment to the Medicaid legislation, which mandated health screening for Medicaid-eligible children. We shall be talking about screening and assessment to a considerably greater extent here. The Welfare Rights Organization has directed attention to the neglect of this legislation in recent years so that now it is more visible, and there are now serious efforts for implementation at the state level. By 1969 our concerns about the comprehensive care of children had moved to the point at which there was Federal recognition of the need for an Office of Child Development. Head Start was moved into that office, and other child care programs have been developed within the framework of that office. I mention these developments because

as a society with a pluralistic approach to problem solving, we have been considering a variety of ways by which we can bring our disciplines and our fragmented services together in some comprehensive framework.

I should mention the numerous commission reports of the latter sixties--commissions on delinquency, on crime, on violence, on civil rights; local commissions like the Cox Commission, which looked into the Columbia disorders; the Walker Commission on public disorders. All of these, it seems to me, tended to point in the direction of one very important thing: that if we were to deal with the social problems of the country, we had to pay more attention to the development of children, particularly young children, and the process by which they develop social relationships. More and more, the consensus of these many reports was that early development was important for later behavior. I mention this, because one can become cynical about the numbers of reports that have been presented; in our society, it seems to me, we need to go through such a process for consensus building. I think the consensus points in the direction of the need for paying some attention to the ecology of the young child.

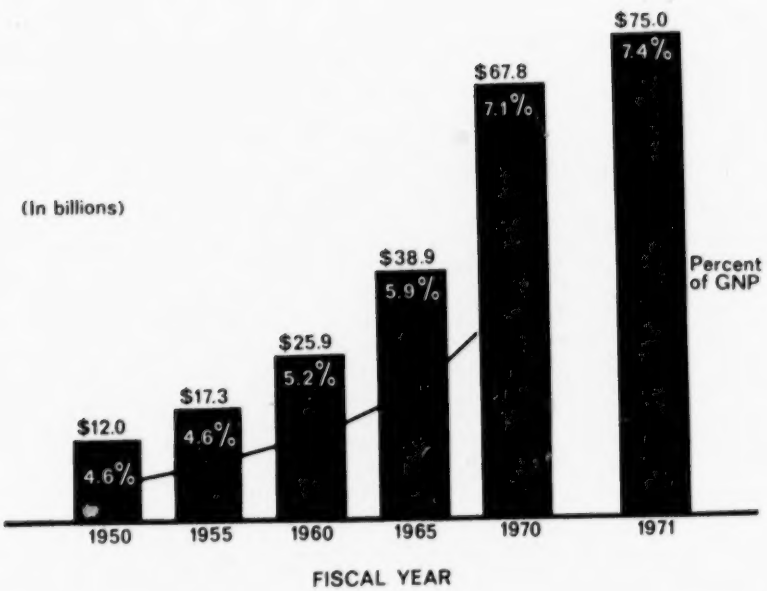
The report of the Joint Commission on the Mental Health of Children focused in a very comprehensive way not only on mental health, but also on the need for comprehensive services of all kinds for children--health, welfare, and education. Indeed, one of the criticisms of that report has been that it is perhaps too broad, too comprehensive; but it did popularize the notion of advocacy on behalf of children; and in the White House Conference on Children in 1970, and the White House Conference on Nutrition and Health, we saw further impetus given to this notion.

There are a couple of other issues that I want to mention very briefly. One is the issue of accountability in our programs, which I think has a very important bearing for this conference. One can look at this in financial terms.

Figure 1 is a chart that I took from the Social Security Bulletin; it illustrates the growth of our national expenditures for health. In 1970 we were up to almost 70 billions; by now it is in the area of 80 billions. In terms of total expenditure that is a large amount, but the more significant figure that I would like to direct your attention to is the percentage of the gross national product--the figure in the bar graph. That was 7% in 1970; it is probably about 8% or a little higher now. The economists are concerned that this will probably reach 10% soon; many of them feel that as a society we cannot go much beyond that point.

What this growth in expenditure means, it seems to me, is that we have to account for what we do more fully than we have done in the past. When we spent 3.6% or 4% of the gross national product for health, we had very little visibility, and we could do almost anything we wished within our system or nonsystem; but we are very visible now and the matter of accounting for what we do becomes more and more significant. Thus, if we are going to propose programs, either reinforcements or extensions of the old, or development of new programs, or combinations thereof, it seems to me that we have to be in a strong position to justify what we want to do. I am not suggesting that we should come up with monolithic approaches to problem solving. But within this framework we also need to realize what the priorities are.

Figure 1


(In billions)
$12.0
4.6%
$17.3
4.6%
$25.9
5.2%
$38.9
5.9%
$67.8
7.1%
$75.0
7.4%
Percent of GNP
1950
1955
1960
1965
1970
1971
FISCAL YEAR

In the Joint Commission report it was pointed out that approximately ten cents is spent for health services for each child in contrast to a dollar spent for each older person. We have, then, set such priorities in very pragmatic ways. Are we willing to become more effective advocates for children; and if we are, can we do this in the context of a balance of human services, rather than as a proprietary interest group? The matter of accountability, I think, is going to loom larger than it has in the past. I am not suggesting by this that we can account in precise quantitative terms for all human service programs; but to the extent that we can, we should; and we should try to be more planful and analytic than we have been in the past.

This leads me to the last point, in a historical sense, that I would like to make for our meeting: that is the tremendous growth in our knowledge of child development, human development, over the past decade. The revolution in biology, which started in the forties, took some time to generate practical implications. By the sixties advances in biochemical genetics led to new knowledge concerning inborn errors of metabolism; cytogenetics has led to new understanding of a large variety of abnormalities; and more recently the developments in immunology--all of these are enabling us to make much more significant contributions to the health of children and, hopefully, to preventive practices than we were able to do in the past. Also, in psychological and social research, because of the tremendous interest in young children and the burgeoning of investigative interests in this field, we have a much more significant body of knowledge today. It is therefore extremely timely that we have come together to assess what it is that we know--what seems to be practical--that has come out of our various research endeavors. We know a great deal now that we did not know before about the effects of various kinds of intervention programs for young children. Out of these, it seems to me, we should be in a position to sort out what is effective, what is relatively ineffective, and what the choices are that we have to make.

The great interest in child development and child care programs in the past decade has attracted the attention of the nation. This is evident, it seems to me, in the passage in 1971 of the Comprehensive Child Development Bill. That it was vetoed by the President is not the point at issue. The fact that such a bill could get through Congress and that the Congress could almost override a veto is to me a manifestation of the very considerable interest of our people in its young children. It is unfortunate that this legislation was tabbed as a day care bill; but it really was a comprehensive child development bill, through which communities at the local level would have been able to establish priorities for children in their own communities. We have also had the Developmental Disabilities Act recently, which is another indication of the very considerable interest and sophistication of our citizens at large as well as of the members of Congress.

We have, then, a tremendous interest and focus on the problems of young children at the present time; and I think we are assembled here to see whether we can make the most of the interest that prevails in the country even at a time when funds for human services are not abundant. Can we develop recommendations that will make for more effective, more adequate programs for infants and children?

I have said very little about screening and assessment, although that is what this conference is about, because I see screening and assessment in terms of the challenge to the development of programs, not only in terms of developmental deviations or defects, but also in terms of helping each child attain his fullest potentialities. I think that we are on the threshold of generating more interest in the development of health, or competence, or mastery as an issue in psychological and social development. When we look at assessment and screening, I think it is important for us to be aware of the fact that we are not focusing exclusively on detecting and correcting developmental defects, but that we are also focusing on enhancing all of human development.

I would like now to move on to the morning plenary session, which the Planning Committee thought would best be developed through a debate in order to get the issues on the table. We are going to have the pros and cons on the physical, social/emotional, cognitive / intellectual, and language factors in the screening and assessment of young children. We have a number of people who have been very significant workers in these vineyards, and we are going to call on them to state their positions. You will all recognize that we have given them too little time, but you will be working on all of these issues in the small work groups throughout the next day and a half, so that there will be opportunity for you to amplify and deal with the issues that are raised.

physical

QUASI-DEBATE PRO

Margaret J. Giannini, M.D.
Professor of Pediatrics
Director, Mental Retardation Institute
New York Medical College
Valhalla, New York

The question that we are faced with today concerns the use of developmental screening devices for early detection of developmental disabilities and my charge is to present some affirmative reasons for such screening in the physical-organic realm of development. I think that the entire concept of early screening and assessment is fraught with promise and difficulties because we do not have the luxury of the many studies that perhaps we should have at this point in time to evaluate and assess some of the screening techniques and some of the assessment procedures that many of us have tried to implement. Of course, as Mrs. Rockefeller and Dr. Richmond eloquently pointed out, this entire field has only begun to mature in the last decade or so. But I think in spite of that there are probably some positive issues that we can at least discuss.

My discussion of this topic will be divided into three parts. First, I hope to show a rather clear-cut need for a screening device, then present a variety of devices, and then discuss a broad range of generalities and their potential significance. I will not try to address myself to the normal standards of growth and development that all of you are certainly sophisticated in, so that when we talk about screening devices we will assume it is in terms of the normal growth and development standards with which we are all very familiar. I might add, as an aside, that I'm terribly glad that I am on the affirmative and do not have the task of Dr. Frankenburg of doing the negative because it is hard enough to present the affirmative without trying to also present the negative. Lastly, I hope to convince you of the advantages of using screening tests to detect developmental disabilities. Let's consider the need to employ a screening device.

We can all agree, I think, that there is a rather substantial portion of the population group, ages 0-5 years, that displays developmental disabilities. These problems range from mental retardation, abnormal growth in fine motor coordination, visual and auditory handicaps, as well as conditions presenting themselves only with subtle soft signs, which are the most common ones that escape us the most often. The actual percentage of the number of children under five with developmental disabilities is likely high, as you well know, but is difficult to determine since these problems very often go undetected by the physician, the parents, the teacher for a very long time, often until the child has reached the age of five.

It would not only be desirable but also important to the future of these children to screen and manage these problems early and in this way to better help them and their families to adapt to or solve the presenting problems of developmental disabilities. Moreover, it is easier to manage a problem detected in its early stages because time lags are proportionate to the time required for habilitation and cure. The question that arises is how best to

solve the problems posed by developmental disabilities. In the case of the individual child, early detection and treatment of the developmentally disabled is imperative.

In the case of the population group under five, in addition to early detection, it is necessary to compile certain demographic data. The incidence of different developmental lags should be determined, especially in the inner-city and in populations of the disadvantaged and minority groups. Innovative and creative methods must be developed for the delivery of services to the mass population with the last amount of effort in manpower. The duration of these lags should be considered. The socio-economic factors must be considered as they are related to developmental disabilities which have environmental implications relative to other important factors, such as malnutrition, child abuse, and child neglect. There are three courses open to us in dealing with developmental problems: 1) we can ignore the problem altogether, as has been done so well in the past by design, lack of interest and/or knowledge; 2) we can deal with these problems only after they become conspicuously manifest; or 3) we can attempt to devise methods for early detection. Let us consider then for a moment some reasons why early identification of physical and developmental disabilities is helpful. In the area of prevention, amniocentesis can permit an antenatal diagnosis of some genetic and biochemical disorders. This permits a decision on the part of the mother, or parents, if you will, to consider with professional support whether or not this pregnancy should be terminated or continued, and if allowed to continue, how they can be prepared for the probable outcome of a severe physically and/or mentally retarded end-product. In addition, since a significant proportion of organic causes are responsible for the etiological factors of mentally retarded and developmentally disabled children, it is imperative that an amniocentesis in concert with genetic counseling be given a closer look in order to better counsel the possible carriers of recessive genes within a given family constellation. O'Brien has stated that there are 27 or more neurological diseases involving severe mental retardation which can be identified and diagnosed during early pregnancy.

For several metabolic disorders, as you well know, the earlier the recognition and the earlier an appropriate treatment is instituted, the better are the chances for a successful outcome. Genetic conditions associated with mental retardation fall into three categories: the chromosomal aberrations, the neuro-ectodermal disease entities, and the metabolic syndromes. Thus it is possible to employ preventive methods with the parents at high risk of conceiving children with developmental disabilities due to biological and organic factors; furthermore, if a defective child is conceived and detected early enough certain steps can be taken to minimize or prevent progression of the developmental disorder. In cases of chromosomal aberrations and neuro-ectodermal disease entities, these can be detected by early and careful examination of the newborn infant. Early detection of the metabolic syndrome is dependent on available history and biochemical screening tests. The aminoacidurias, such as phenylketonuria, which is best known to all of us as a metabolic disease entity number one, errors of carbohydrate metabolism, the lipoidoses, the leukodystrophies, the endocrine diseases, and serotonin syndromes should also be investigated and identified early in order to treat and prevent the severity of disability that is often encountered in these syndromes.

Screening observations of the premature child are extremely important and valuable, since central nervous system disorders are often found years later, much too late to correct. They are frequently missed in premature infants because of ineffective screening and monitoring of physical signs of development. Early detection of these disorders could have meant more effective treatment and a possible minimization of the disability.

Visual and audiological screening, although difficult to perform early in an infant's life, is an invaluable factor in chartering a child's development. It is stated that hearing loss and deafness may be affecting as many as 100,000 school-age children in the United States.

Screening for fine and gross motor skills is a basic indicator of developmental landmarks. Screening can also be an aid in detecting parental mistreatment. A battered child, for instance, would not pass unnoticed by an alert examining physician.

Of course, it would be naive to argue that there are not a number of problems in developmental screening. The recitation of these problems, however, must not be counted as an argument against developmental screening. The idea of screening is a sound one. The problems involved must be understood and solved, but screening itself must be continued and constantly refined and reassessed. Consider for a moment the risks of failing to provide adequate developmental screening. The child may suffer unnecessarily severe physical handicaps as a result of undetected incipient problems which are subsequently detected too late for efficacious treatment. Mental disorders may be caused by the affect of untreated physical disabilities. Parents may be initially shocked and permanently disturbed by the sudden realization of their child's developmental disabilities.

I believe the pediatrician, especially, should more systematically evaluate physical developmental status. I think it is important that this be done just as well as immunizations are recorded. Even though a refined instrument for screening may not be used, such routine screening could at least lead to the recognition of gross developmental disorders, and evidence is accumulating that routine gross screening procedures help to identify developmental problems earlier than without its use at all. The advantages of early detection are twofold: 1) it is possible that a treatable condition exists; and 2) parents can be made to realize the limitations of their child at an earlier stage and with anticipatory guidance and counseling to parents it may be possible to avoid some of the emotional complications that tend to occur later in children with handicaps. Hopefully, the child would be able to gain early successes and not failures as so many of them tend to have.

I would like to share with you some of our recent experiences that we have had with our Rapid Developmental Checklist. We instituted the routine use of this in a health station in a ghetto area of New York City, and in the past nine months we have processed 3,000 children who routinely come in to the health station. We have picked up sixteen children with this Rapid Checklist, which I call the Laundry List, and some have been definitely diagnosed as being mentally retarded. The significant factor is that the year before the checklist was in operation there was not one single case referred for any developmental disability.

I think that it is important for us to recognize that with any screening device. Routine and systematic screening is the best possible means for insuring early detection of physical disabilities. The early detection of physical defects can hopefully lead to a correction of the problem or a more effective program of treatment. Data compiled from individual physicians can be helpful in charting the overall occurrence of particular disorders. This data can be used to point out and provide special care for high-risk clusters of the population. The data can further be used in research projects concerning the causes of physical disorders.

Aside from these particulars, the main advantage of developmental screening devices is that they deal directly with the problems of the physical disability rather than ignoring them. Screening techniques are really short and relatively simple devices which sharpen the observation of irregular development, provide gross cut-offs for various developmental levels, elucidate lags and spurts in development, and help cluster strengths and weaknesses. Of course there are limitations but these limitations can be overcome by continued refinement.

I have attempted to demonstrate the need for early detection of the physical disabilities, and I have offered just a few tests that tend to be used to detect these disabilities. I think the advantages of screening devices naturally far outweigh the risks. What I am also really saying is that if we are going to accomplish what we have set out to do in early detection for early treatment to avoid the monumental problems of full-blown developmental disabilities, it is not enough to develop all of the special techniques, but we have to develop keener awareness and more positive attitudes toward early detection and intervention.

physical

QUASI-DEBATE CON

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I interpreted my assignment to be a negative approach toward physical examinations as a method of identifying children with developmental disabilities. Contrary to the other speakers, I have not performed research in the area of physical examinations as a screening procedure. Furthermore, I had difficulty in approaching the subject of physical assessment as a "screening procedure" since I interpret physical assessment as a "diagnostic procedure" and not a screening procedure. In exploring this subject it may be well for us to review the yield of routine physical assessments in the identification of handicapping conditions. Next we shall discuss the implications of uncovering these particular problems upon the future development of children. Finally, we shall discuss how well these particular problems or conditions that are discovered in the physical assessment meet criteria for the selection of diseases for which one might screen. In conclusion, we shall discuss alternative approaches to physical assessment as a method of screening for developmental disabilities.

Dr. Frederick Anderson reported in Pediatrics a study in which he asked pediatricians providing routine infant care to make a tally of newly uncovered health problems each time that they provided well child check-ups during the first year of life. He reported results of 6,668 examinations. 762 children were found to have abnormalities of which only 130 or one percent were found to be "significant." Half of these significant problems were discovered by the time the infant was two months of age and 80 percent were uncovered by the time the child was six months of age. The most common problems that were found were congenital heart disease, of which 60 percent was found by two months of age, 100 percent by six months of age. Another problem which has relevance to developmental disabilities is the strabismus which was noted in 1.3 percent of the children. Another problem was failure to thrive. Though it is recognized that about 3 percent of children are mentally retarded, and though many retarded can be identified during the first year of life, the prevalence of developmental delays was only .09 percent. One may well speculate that the physicians failed to identify one of the most serious developmental disabilities, namely, mental retardation.

Dr. Robert Hoekelman reported a review of findings as a result of physical assessments of Head Start children. 544 Head Start children underwent physical assessments. As a result, 58 defects were uncovered; of these 14 or 2.5 percent were found to be significant. For instance, they "uncovered" 9 cases of heart murmurs, but only one of these was significant, giving a yield of 0.1 percent. They found two cases of strabismus which were both significant, giving a yield of 0.4 percent. There were three other problems, but none of these were interpreted as being significant. The total yield of new significant health problems uncovered was therefore very low among these Head Start children.

A third study of the yield of physical examinations was performed upon six-year-old children. Yankauer reported upon the results of 1,056 physical examinations of first-grade students. Though this study involves children who are a little beyond the age limit of our discussion, the findings nevertheless have implications for us since the prevalence of significant health problems increases with age. Of the 1,056 children who were examined, only 21 children were found to have problems that had not been identified previously. The yield therefore was 2 percent. Most of these problems were orthopedic in nature. For instance, flat and pronated feet were uncovered. Other less prevalent problems were a mesentery cyst, and a residual polio paralysis. The majority of the remainder fell into categories of emotional problems, ear, nose, and throat problems, and one seizure disorder. Each of these were not discovered as a result of the physical assessment, but instead were uncovered by the medical history. Yankauer's conclusion was that complete examinations of this entire grade was valueless from a case-finding standpoint.

Having discussed the yield of routine physical assessments, for purposes of today's discussion we should review the types of problems uncovered and their implications upon their becoming developmental disabilities. As you remember, the main maladies uncovered in these examinations were emotional problems, strabismus, cardiac defects, and seizure disorders.

With that as a background, I would like to discuss the criteria to be considered in deciding what you are going to screen for. These criteria are taken from our forthcoming book entitled Pediatric Screening Tests. You might not agree with all of the criteria. The first of the criteria is that the condition that you are screening for should be serious or potentially so. Strabismus certainly is serious. It has implications beyond a cosmetic condition, because 60 percent of amblyopia is due to strabismus. Amblyopia is a condition in which children develop a permanent impairment in vision due to disuse of an eye which in turn is because the child sees double. The child with strabismus or eyes that are not straight will tend to block out the vision of one eye to avoid seeing double. Permanently reduced vision certainly qualifies as a serious developmental disability. Though there are many types of congenital heart disease, one could say that these are generally serious. Similarly, the other conditions uncovered by physical assessments are serious. The second criteria is that the problem can be identified with sufficient accuracy so as to separate those individuals who have the disease from those who are free of the disease. One of the problems in looking for emotional problems in children is that sometimes it is difficult to obtain agreement as to who has the emotional problem and who does not. Though the experts agree on the very normal and the extremely abnormal, they often disagree in the classification of individuals who fall between the very normal and the very abnormal.

The next criterion is that the prognosis should be improved if the disease is detected and treated during the asymptomatic stage. Some types of congenital heart disease would satisfy this criterion. On the other hand, the flat feet and other orthopedic problems, the allergies and seizure disorders would fail to meet this criterion.

Figure 1 (Frankenburg, 1973) is a schematic representation of the biological onset of a disease, the asymptomatic stage, the symptomatic stage,

Asymptomatic and Symptomatic Stages of Disease

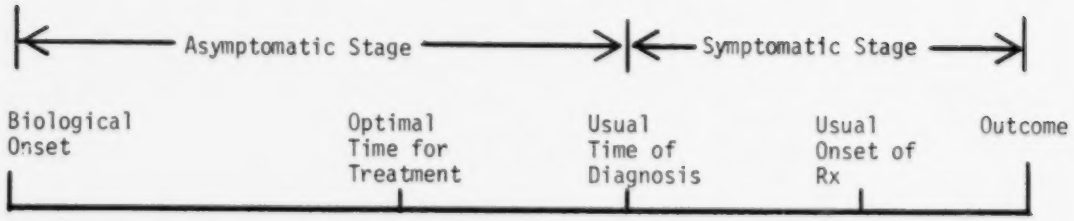

Fig. 1

From Frankenburg, W.K. and Camp, B.W.: Pediatric Screening Tests, Charles C. Thomas & Company. In Press.

and the final outcome of the disease process. Screening in this country is primarily aimed at facilitating the diagnosis during the asymptomatic stages of disease. The justification for screening is built on the premise that treatment during the pre-symptomatic stage will improve the outcome more than treatment first begun during the symptomatic stage of the disease process. For emotional problems, there is considerable evidence that early intervention would be more efficacious than waiting until the children are symptomatic. Likewise, strabismus which may produce secondary amblyopia is best treated before signs of amblyopia appear. Most congenital heart disease is also best treated prior to the development of secondary problems and symptoms.

Another criterion to consider is that the disease or condition should be treatable or controllable, since there isn't any sense in screening if the condition isn't treatable or controllable. I think all of these conditions uncovered on the physical assessments meet this criterion.

The next criterion is that there should be adequate screening time. Screening time is the interval between which the condition can first be detected with a screening test and the time of optimal results from treatment. In phenylketonuria the optimal time to initiate treatment is during the first month of life. The onset of treatment after that time generally is less effective in the prevention of mental impairment. Screening time in PKU is therefore the time between birth and one month. The screening time for seizure disorders is zero since the condition is rarely detected in asymptomatic individuals. Dr. Anderson's study has demonstrated that congenital heart disease can be identified during the first month of life prior to the time when many infants have developed symptoms of cardiac disease.

Another criterion is that the condition should be relatively prevalent. Screening for rare diseases or disabilities increases the cost of identifying the rare individual who has the particular problem. In view of the low yield of physical examination in finding serious pathology in asymptomatic individuals, this criterion is not met by most conditions detected by a physical examination.

The next criterion is that there should be facilities to diagnose and treat individuals suspected of having the disability. Obviously, there is no value in screening if no facilities are available to rule in or out the diagnosis or if no treatment is available. The only justification might be to utilize screening results to develop needed diagnostic and treatment services. In considering the value of physical examinations to detect developmental disabilities, it is important to be aware that the major developmental problem afflicting children is frequently not detected by a physical assessment. The problem of which I speak is developmental retardation. A number of studies bear out this statement. Dr. Barbara Korsch studied the accuracy of pediatricians' estimates of children's IQs. She found that even the most experienced physicians failed to identify children with intelligence quotients below 70. Drs. Bierman and Connor compared pediatricians' assessments with Cattell IQ scores of 20-month-old infants. The physicians only identified three of the eleven infants who had IQs below 70. The physicians' assessments therefore yielded sensitivity of only 27 percent in identifying all of the infants with IQs below 70. Such findings

are also supported by prevalence data on mental retardation. Such data indicate the prevalence to rise sharply when children reach school age. This is partially because the development of most preschool-aged children is not adequately assessed. Therefore the mentally retarded are not identified.

In contrast, aides trained to screen the development of children residing in the poverty areas of Denver have screened over 12,000 children. By utilizing the Denver Developmental Screening Test, the aides achieved a sensitivity, or 92 percent accuracy, in identifying all of the individuals who had IQs and DQs below 70. Similarly, they achieved a 97 percent specificity, or accuracy, in identifying those individuals who had intelligence and developmental quotients above 70.

In conclusion, I would say that the physical assessment is not an appropriate use of manpower in the detection of developmental disabilities of children. In fact, I wouldn't even call physical assessment a screening procedure if one defines screening as the application of rapid and simple procedures to identify those individuals who are highly likely of harboring the disability or disease in question. Instead, I consider a physical assessment to be a diagnostic procedure. Furthermore, I would conclude that the problems that are uncovered with physical assessment have little bearing on the future development of children. In fact, the most important problems--such as mental retardation and developmental deviations--are not uncovered by physical assessments. Instead of physical assessments I recommend the use of medical histories and the application of developmental screening tests and eye screening tests to detect the children with developmental disabilities.

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cognitive/ intellectual

QUASI-DEBATE PRO

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Mrs. Rockefeller, Dr. Richmond, I am pleased to be here. I have a feeling that Dr. Meier may have had a weapon over my head when he asked me to come to this conference. As you see, it was also contingent upon presenting the positive side of this question on early screening and assessment in the Cognitive/Intellectual Area. (Parenthetically, this assignment requested "that each speaker structure his remarks around consideration of current materials and procedures, technological aids, manpower training requirements, populations giving highest yield, related demographic considerations, ethical and legislative constraints, and other related considerations he may have on the basis of knowledge and experience in this particular developmental area.")

Let me begin by saying that my analysis of this task is simply this: Is it possible to identify the types of knowledge or the processes or means by which the young infant and child acquires and uses this knowledge? Now it's quite clear that my answer to this proposition is an emphatic yes. And as a forward to what will follow, I want to state a number of presuppositions which will define my position on early screening and assessment. You should know that I am a developmental psychophysiologist and obviously the biological aspects do come in to play. Now first, I am assuming that the precursor of effective cognitive functioning is a functional nervous system. Secondly, that infancy is a critical period in intellectual growth. Thirdly, that theory should serve as a frame of reference to guide any assessment procedure. And, fourthly, that there is in existence a body of normative material which will serve as a standard against which to derive a clinical impression as to whether a child's performance is or is not indicative of a developmental disability. Now, from these viewpoints I bring my emphasis on screening and assessment. I wish to stress again that this is going to be based on both psychophysiological and behavioral measures, with a focus primarily during the period from birth to somewhere around 12 months.

Let us begin by pointing out that the biological substrate which is the precursor of efficient cognitive functioning can be described by Figure 1. You will note that we have essentially a computer model with input processing and output components. As we look at this, it calls our attention to the existence of mechanisms that represent preprogrammed structures for regulating behavior. These correspond to the receptors, the central processor, and the effector segment. Now these structures are designed for information processing, and by information processing I mean the reception, analysis, and

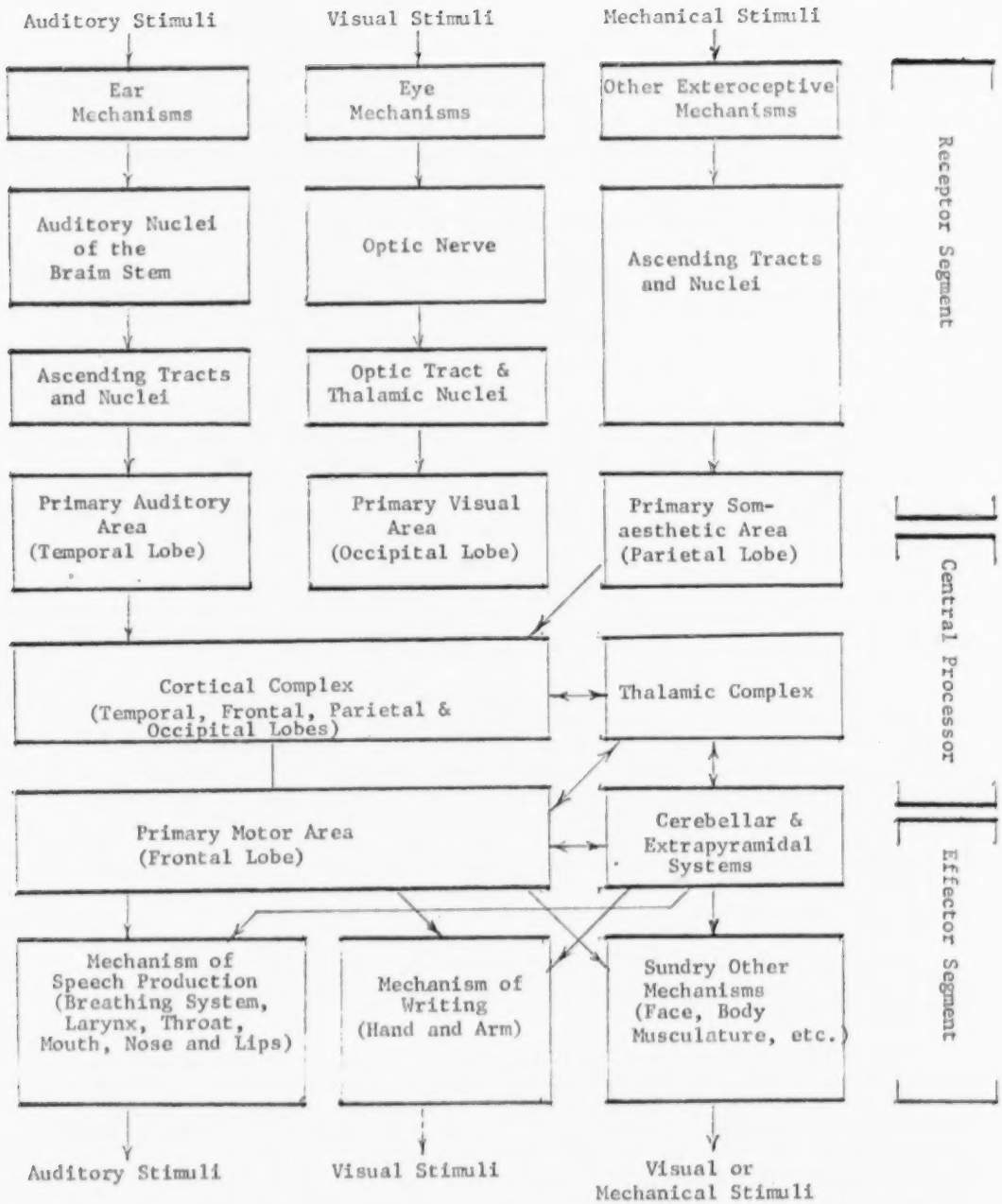
Auditory Stimuli
Visual Stimuli
Mechanical Stimuli
Ear Mechanisms
Eye Mechanisms
Other Exteroceptive Mechanisms
Receptor Segment
Auditory Nuclei of the Braim Stem
Optic Nerve
Ascending Tracts and Nuclei
Ascending Tracts and Nuclei
Optic Tract & Thalamic Nuclei
Primary Auditory Area (Temporal Lobe)
Primary Visual Area (Occipital Lobe)
Primary Somaesthetic Area (Parietal Lobe)
Central Processor
Cortical Complex (Temporal, Frontal, Parietal & Occipital Lobes)
Thalamic Complex
Primary Motor Area (Frontal Lobe)
Cerebellar & Extrapyramidal Systems
Effector Segment
Mechanism of Speech Production (Breathing System, Larynx, Throat, Mouth, Nose and Lips)
Mechanism of Writing (Hand and Arm)
Sundry Other Mechanisms (Face, Body Musculature, etc.)
Auditory Stimuli
Visual Stimuli
Visual or Mechanical Stimuli

Figure 1: Schematic diagram of neural mechanisms for human communication. (From Human Communication and its Disorders - an Overview, 1969) (Crowell, 1972).

interpretation of stimuli. And it is quite clear from our definition that these structures are activated by the peripheral receptor, and in particular, the auditory, visual, and haptic modalities. Since analysis and interpretation are difficult to study in young patients, sensory reception becomes a critical precursor of later cognitive functioning. In light of this our approach is first to determine whether a newborn significantly responds to energy change or stimulation within these three modalities.

Sophisticated biomedical instrumentation and computer analysis makes this feasible. First I would like to run through this slide so you are looking at the same things I am. These represent heart rate (HR) responses; these electroencephalographic (EEG) responses. In the first one we are referring to stimulation by modulated pure tones, this by 40 and 75 watt lights and essentially what one might refer to as an air puff. I also would like to remind you that these are confidence intervals. Here you will note time of stimulus on, and when I refer to exceeding the confidence limit, I mean things (response magnitudes) of this sort. Now, to go along....as you see in Figure 2, both heart rate and the EEG are indicators of significant changes to sound, lights, and tactile stimuli. Here you will note that a response, in this case the HR level, is described with reference to these confidence limits and the time of stimulus onset. The deceleration of about one second and the acceleration of about two seconds are significant changes relevant to these confidence limits. Likewise, if we look at the EEG we find that we have response patterns associated with a significant change occurring somewhere between 200 and 400 milliseconds for tones, lights, and the air puff. Since we must move on, I can't say very much more. I think the point is quite clear. One can detect sensitivity to sensory stimuli in these three modalities.

Along with determining sensory sensitivity, I would suggest that some measure of hemispheric functioning is desirable for assessing present and subsequent neurological development. Now in this case, we use cerebral responses to visual stimulation. Figure 3 is an example of the results that are seen in a two-day-old female neonate. Again, let me run through this very briefly. Here are the prestimulus and poststimulus periods and then a test of the difference between these. The comparison illustrates only right hemispheric driving to a stimulating frequency of three flashes per second. I am sure that most of you know that in the adult we expect and usually do get a bilateral response or significant driving on both sides.

In Figure 4 we are interested in comparing the pre- and post-test results. These represent the two hemispheres and we have driving, as indicated, in both hemispheres.

In addition to these two measures of early sensitivity and cerebral development, I believe a measure of the orienting response (OR) is necessary. The OR has emerged as an important variable which can be related to both attention and learning. As you know, the OR can be described as the response to new events occurring in the immediate environment. A description of the set of neurophysiological processes involved in the OR is as follows: with a new stimulus, cortical analysis takes place to determine if the stimulus is novel. Then there is either a subsequent inhibition or excitation of other systems, most notably the autonomic system. Our search for the OR is reflected in Figure 5 which shows the relative change and time relationship for both the EEG and HR. The one reflects cortical processes between 200-400 msec

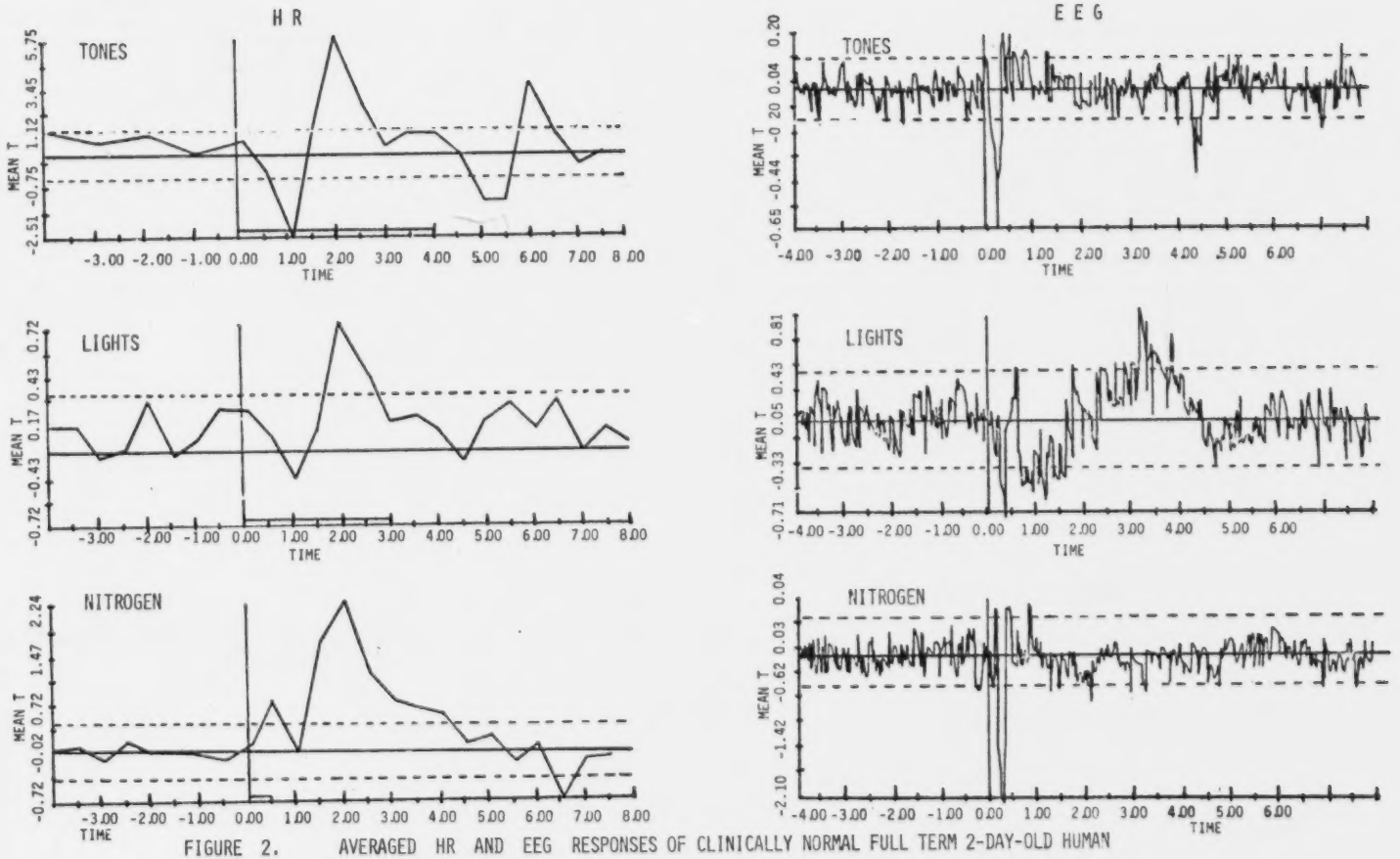

FIGURE 2. AVERAGED HR AND EEG RESPONSES OF CLINICALLY NORMAL FULL TERM 2-DAY-OLD HUMAN NEWBORNS TO LIGHTS AND NITROGEN PUFF WITH TIME OF SIGNIFICANT RESPONSE DEFINED IN TERMS OF 0.05 CONFIDENCE LIMITS. (UNPUBLISHED DATA).

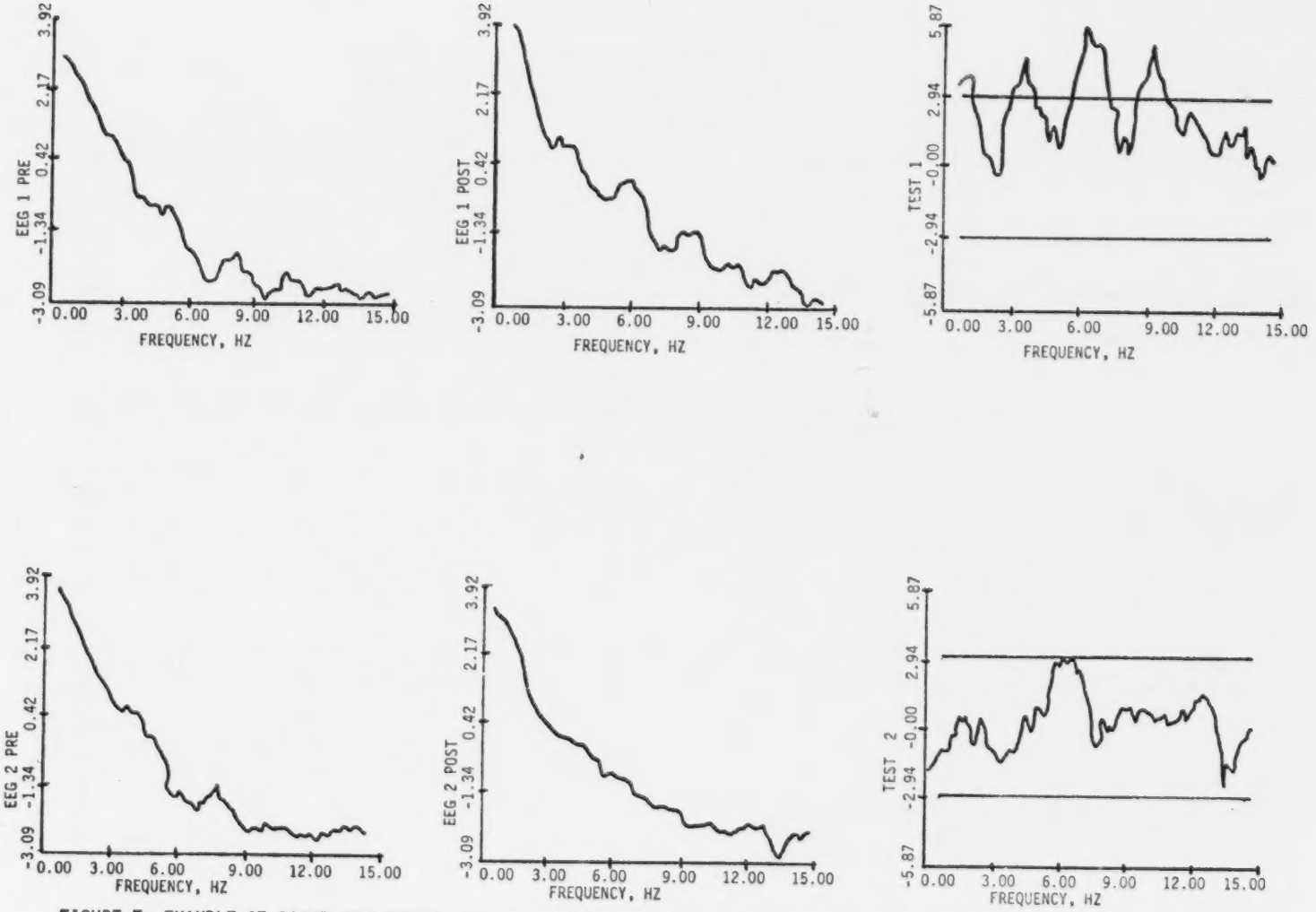

FIGURE 3. EXAMPLE OF RIGHT UNILATERAL DRIVING IN TEST 1 TO BILATERAL PHOTIC STIMULATION AT 3 FLASHES PER SEC FOR 4 SEC. (UNPUBLISHED DATA)

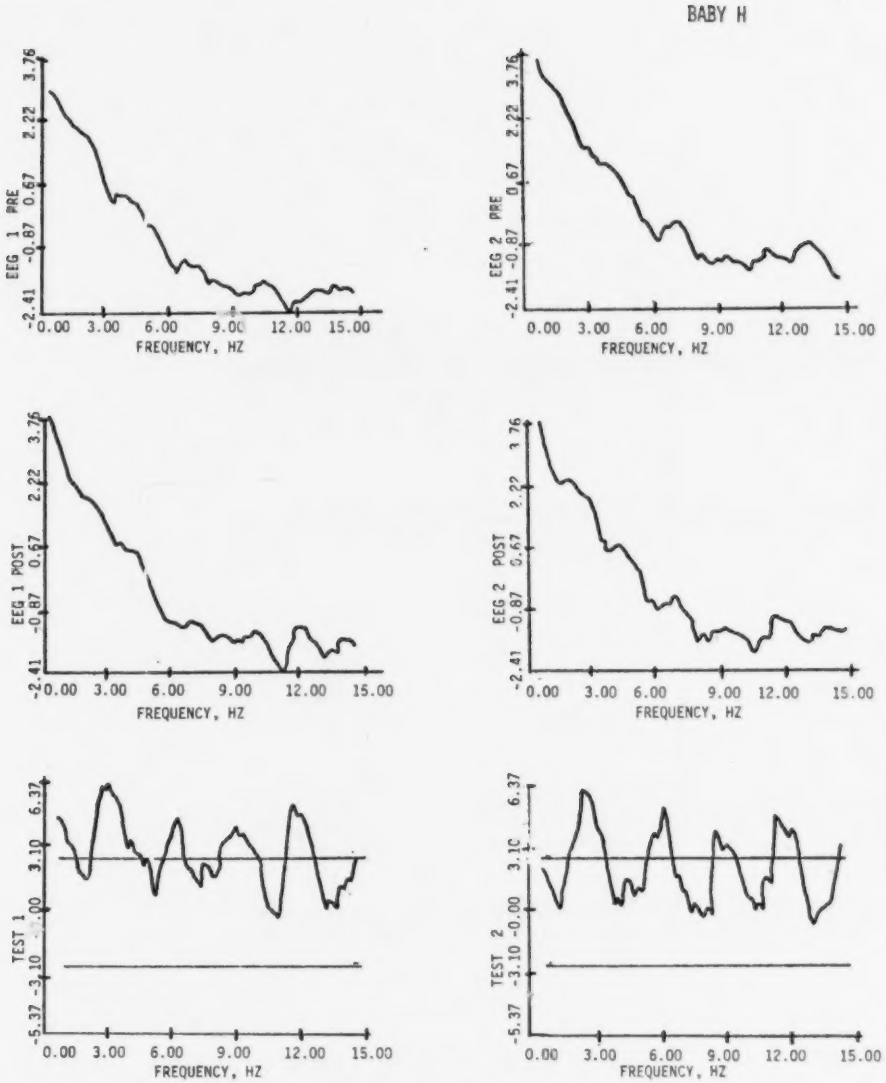

FIGURE 4. EXAMPLE OF BILATERAL DRIVING IN TEST 1 AND TEST 2 TO BILATERAL PHOTIC STIMULATION AT 3 FLASHES PER SEC FOR 4 SEC. (UNPUBLISHED DATA).

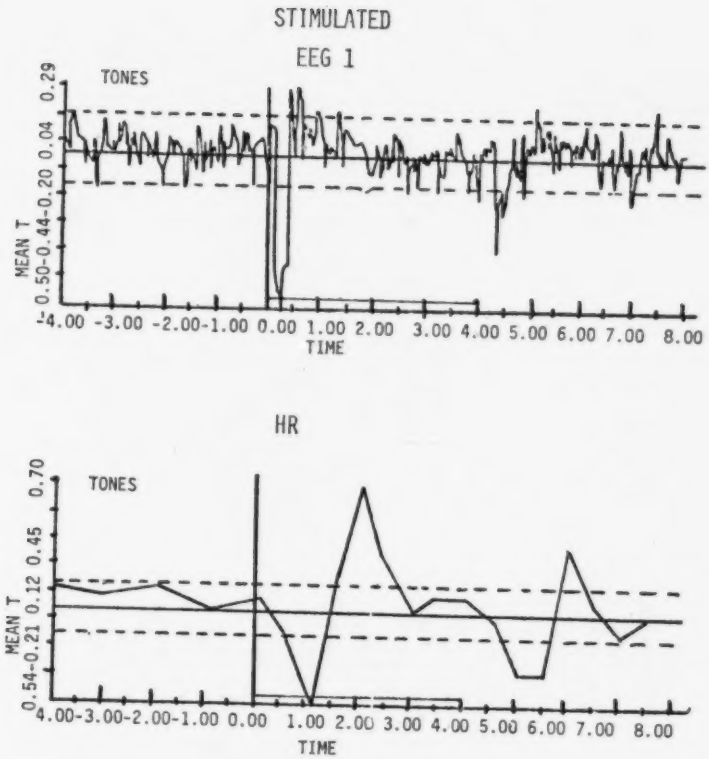

FIGURE 5. DEFINITION OF ORIENTING RESPONSE IN TERMS OF AVERAGED HR AND EEG SCORES ILLUSTRATING CORTICAL RESPONSE BETWEEN 200-400 MSEC FOLLOWED BY HR DECELERATION. (UNPUBLISHED DATA).

and the other autonomic change in HR about 1 sec. Again note the relative deceleration, a pattern associated with stimulus intake, awareness, or attention.

This phase of early screening can be summarized briefly as in Figure 6. This form incorporates one aspect which we record, which I want to call to your attention, and that is gestational age. You will note that we have two parts in Chart 1, a pediatric type of analysis; the other a psychophysiological approach. Here gestational age follows the form outlined by Dubowitz, Dubowitz and Goldberg (1970).

Now there is little question as to the importance of defining the precursors of cognitive functioning. While they are significant in and of themselves, the broad span of cognitive functioning requires additional assessment. There have been two notions which have significantly affected the assessment of infant cognition. The first consists of steps towards clarifying the content of infant tests; and the second are Piaget's notions of ordinality with respect to intellectual development. The work of Meyers and Dingman (1960) and Stott and Ball (1965) are examples of contributions on the early structure of abilities. Their results supply us with

(1) a factorial description of the abilities of infants and young children

(2) they established evidence on the early appearance of hypothesized factors

(3) they determine that test items conceived of as motoric in nature can be interpreted as intellectual or psychological and they reflect "thinking processes" in infants as young as three months.

In Figure 7 is an outline of Meyers and Dingman (1960). They present a number of factors 1-7. The important thing to me is that beginning as early as one month, and those of you who know newborns realize that you can see these response patterns earlier than one month, there are some cognitive abilities that can be tapped.

The next sheet shows the Stott and Ball (1965) summary. They reflect a description of abilities as formulated in terms of Guilford's (1959) scheme. If you go down through Figure 8 with me you will observe that abilities such as cognitive memory can be observed as early as three months.

The Piagetian (Flavell, 1963) approach is known to all of you. In Figure 9 is an outline of sensorimotor period for about four major components. The point for me to stress is that beginning as early as four to eight months we find evidence of certain concepts, of the ability to handle certain types of material. The Piaget scales have been developed by Uzgiris and Hunt (1966) and they have been used by Wachs, Uzgiris, and Hunt (1971) to assess concepts which infants have learned. Now the point of this discussion is to remind you that there are items available for early assessment.

The mode of clinical assessment I visualize is a package compiled by the clinician and focused on producing objective information as to whether

SUMMARY CLASSIFICATION SHEET
(Nursery)

PEDIATRICS		PSYCHOPHYSIOLOGY	
GESTATIONAL AGE	Premature Small-for-date Mature Postmature	AUDITORY SENSITIVITY	present - absent
DETRIMENTAL FACTORS	Normal adjustment Marginal adjustment Poor adjustment	Tones 80 db 63 db	
		Click	present - absent
NEUROLOGICAL	Normal Abnormal	VISUAL 40w - 70w	present - absent
		TACTILE	present - absent
		OLFACTORY	present - absent
		ATTENTION (Orienting Reflex)	present - absent
		HEMISPHERIC FUNCTIONING (Unilateral/Bilateral)	present - absent

OVERALL IMPRESSION: NORMAL ADJUSTMENT, MARGINAL ADJUSTMENT, POOR ADJUSTMENT

FIGURE 6. SUMMARY CLASSIFICATION SHEET (NEWBORN PSYCHOLOGICAL RESEARCH LABORATORY, UNIVERSITY OF HAWAII, HONOLULU, HAWAII).

FACTOR DOMAINS

Early Appearance	Hypothesized Factors, CA 4-6 Yrs		Age of Emergence of Factors
Domain 1: Psychomotor, whole-body	1.1	Postural Balance	1½ years
1 month: Chin-up			1½ years
5 months: Rolls over	1.3	Impulsion	2½ years
Domain 2: Psychomotor, hand-eye	2.1	Static precision	3 years
3 months: Retentive grasp	2.2	Dynamic precision	3 years
4 months: Grasps and secures			
Domain 3: Visual perception	3.1	Perceptual speed	18 months
1 month: Pursuit movements			
5 months: Recognition of parents	3.2	Space	36 months
Domain 4: Auditory perception	4.1	Auditory discrimination	1½ years
1 month: Awareness			
5 months: Localization	4.2	Auditory localization	1½ years
Domain 5: Receptive psycholinguistics	5.1	Auding	1 year
1 month: Quieted by voice			
3 months: Vocalization to voice			
Domain 6: Expressive psycholinguistics	6.1	Articulation	1½ years
1 month: Noncrying vocalization	6.2	Semantic fluency	2 years
6 months: Babbling			
Domain 7: Mental (memory & thinking)	7.1	Memory span	2½ years
8-9 months: Piaget's "fourth stage"			
10 months: Imitation			

FIGURE 7. FACTOR DOMAINS (MEYERS & DINGMAN, 1960)

SUMMARY OF FACTOR INTERPRETATIONS

WITH COMPARISONS OF TESTS AGE LEVELS

FOR INTERPRETED FACTOR CONTENT

| INTELLIGENCE FACTOR | AGE LEVEL (MONTHS) | | |

DEVELOPMENT OF INTELLIGENCE DURING THE SENSORIMOTOR PERIOD (PIAGET)

Developmental Unit	Object Permanence	Space	Time	Causality
Sensorimotor Schemata (0-1 mo.)				
Primary Circular Reactions (1-4 mo.)				
Secondary Circular Reactions (4-8 mo.)	X	X	X	X
Coordination of Secondary Schemata (8-12 mo.)	X	X	X	X
Tertiary Circular Reactions (12-18 mo.)	X	X	X	X
Invention of New Means (18-24 mo.)	X	X	X	X

FIGURE 9. EXAMPLES OF CONCEPTS DEVELOPED DURING THE SENSORIMOTOR PERIOD AS DEFINED BY PIAGET.

an ability is or is not present. The point is not to obtain a score with it, a DQ or IQ or MA, but a description of functioning abilities. Figure 10 outlines the possibilities that we have discussed.

I think I should remind you that any assessment is incomplete unless some measure of learning is incorporated.

Habituation or the progressive decrement in response to a repetitive stimulus as in Figure 11 appears to offer the most direct approach to estimating learning capacity. Customarily this has involved presenting S_1 with the exponential fall-off, then S_2, the new stimulus, producing an increased level of response. The discrepancy principle of Kagan (1972) offers a broader extension of this model. Collard and Rydberg (1972) provide a simple means of exposure to toys which taps the generalization of habituation to size, color, and/or form by human infants.

The assessment procedures which I have reviewed vary in scope. Clearly, the psychophysiological measures are more expensive--involving equipment and computer time. Personnel required are a nurse and additionally, an assistant practical nurse. Also, a psychophysiologist is necessary. After training, behavioral assessment can be done with well-trained and bright paraprofessionals, at the BA level, under the supervision of a professionally trained individual, at the MA or Ph.D. level.

The point has been made that there is a population which is likely to provide the largest group of children at developmental risk. These findings underscore the importance of identifying premature infants as being at risk for many different developmental disabilities and of following them closely because of the high probability of their developing handicaps whose severity is typically directly proportional to the severity of their low birth weight. The enormity of the problem can be seen from this description of birth weight trends. For all births, the proportion weighing 2,500 grams or less at birth increased slowly from 7.5 percent in 1950 to 8.3 percent in 1965 and 1966. For 1967 it was only slightly less, 8.2 percent. For the year 1967 alone, this represented about 288,000 live born infants who, by definition, are low birth weight infants.

The proportion of low birth weight among white infants varied only from 6.7 to 7.2 percent in the study period...for white infants, therefore, there is no evidence of any marked increase or prolonged increasing trend in the proportion of low birth weight infants: it was roughly 7 percent throughout this entire period.

The data for other infants differ in two respects. First, even in the earliest year shown (1950), the proportion weighing 2,500 grams or less at birth (10.2 percent) was significantly higher than that of white infants (7.1 percent), and it remained consistently higher through the 18-year period. Second, the difference between the two color groups has increased progressively. By 1967, when the proportion of low birth weights among white infants was the same as in 1950 (7.1 percent), the proportion for other infants was 13.6 percent compared with 10.2 percent in 1950 (The percentage distribution is shown in Figure 12, I should call to your attention the fact that the 5.1 figure represents the nearly two-thirds of the immature (low birth weight) births which fell in the weight group 2,001-2,500 grams.).

SUMMARY CLASSIFICATION SHEET

(3 - 6 MONTHS EVALUATION)

Behavioral Assessment A	B	C
Domain 1 (Psychomotor)	Cognitive	Object
Domain 2 (Psychomotor)	Memory	Space
Domain 3 (Visual Perception)	Divergent	Time
Domain 4 (Auditory Perception)	Convergent	Causality
Domain 5 (Receptive Psycholinguistics)	Evaluation	
Domain 6 (Expressive Psycholinguistics)	Others	
Domain 7 (Mental-Memory & Thinking)		

FIGURE 10. SUMMARY CLASSIFICATION OF TESTS AVAILABLE FOR BEHAVIORAL ASSESSMENT FROM 3-6 MONTHS

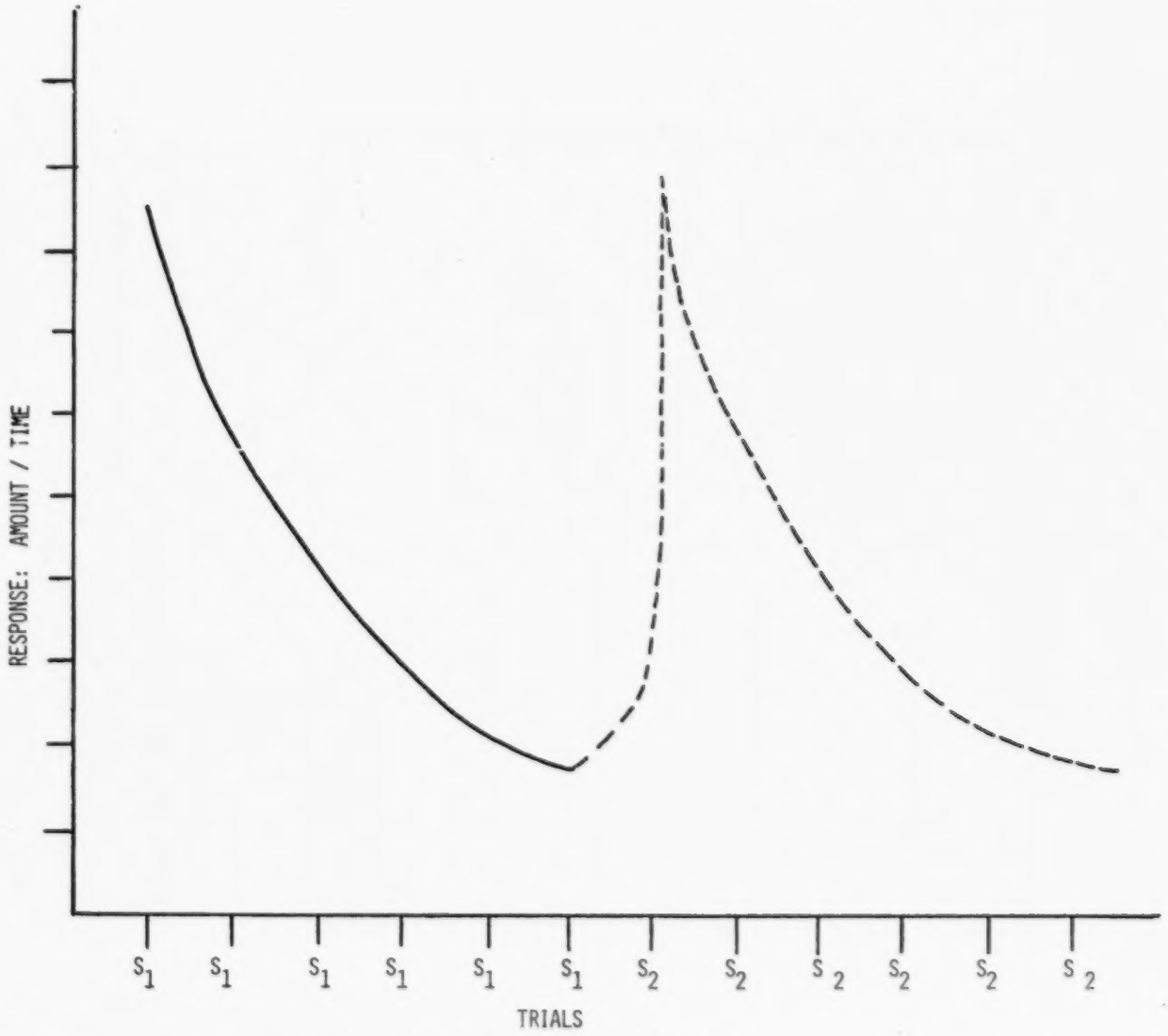

FIGURE 11. ILLUSTRATION OF HABITUATION AND DISHABITUATION.

Color and sex	Total	Birth weight									Median weight in grams[1]	Percent weighing 2,500 grams or less
		1,000 grams or less	1,001 to 1,500 grams	1,501 to 2,000 grams	2,001 to 2,500 grams	2,501 to 3,000 grams	3,001 to 3,500 grams	3,501 to 4,000 grams	4,001 to 4,500 grams	4,501 grams or more		
	Percentage distribution											
Total	100.0	0.6	0.7	1.5	5.1	18.5	33.0	29.8	7.5	1.6	3,310	7.8
Male	100.0	0.6	0.7	1.4	4.5	15.6	30.3	33.5	9.2	2.0	3,370	7.1
Female	100.0	0.6	0.6	1.5	5.7	21.3	35.7	25.9	5.6	1.0	3,260	8.5
White	100.0	0.5	0.6	1.3	4.5	17.2	33.1	33.2	8.0	1.6	3,340	6.8
Male	100.0	0.5	0.6	1.2	4.0	14.6	30.1	37.0	9.9	2.1	3,400	6.3
Female	100.0	0.5	0.5	1.3	5.1	20.1	40.3	25.2	6.0	1.0	3,280	7.4
All other	100.0	1.0	1.2	2.5	8.3	25.3	37.1	18.9	4.6	1.3	3,160	12.9
Male	100.0	1.0	1.1	2.3	7.2	22.4	37.4	21.3	5.6	1.5	3,210	11.7
Female	100.0	1.0	1.2	2.6	9.3	28.1	36.8	16.4	3.6	0.9	3,110	14.2

[1] Rounded to the nearest 10 grams.

FIGURE 12. PERCENTAGE DISTRIBUTION OF LIVE BIRTHS BY WEIGHT, RACE AND SEX.

National Center for Health Statistics: A Study of Infant Mortality From Linked Records by Birthweight, Period of Gestation, and Other Variables. United States. Vital and Health Statistics. DHEW Pub. No. (HSM) 72-1055 Series 20-No. 12. Public Health Service, Washington. U.S. Government Printing Office, 1972

This low birth weight group should be supplemented with fetuses or neonates of high-risk pregnancies, that is, prospective mothers "...who have or are like to have conditions associated with childbearing which increase the hazards to the health of the mothers or their infants (including those which may cause physical or mental defects in the infants)" and/or two, "...in which the prospective mother comes from a low-income family..." (Public Law 88-156, 1963). It goes without saying that established procedures for safeguarding the rights of patients involved should be routinely followed. Thank you.

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⬅ ⇨ cognitive/intellectual

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QUASI-DEBATE CON

To ask a person who has been engaged in the longitudinal assessment of cognitive development to speak <u>against</u> early cognitive screening is comparable to a situation in which a Catholic priest is asked to speak against the Church. But when it is remembered that the present topic is <u>pitfalls</u> in early cognitive screening, an acknowledgment of needs and deficiencies is viewed as appropriate.

You may ask, "Why do we screen?" The reply is: Because cognitive assessment serves four major purposes. These are:

> "1. to describe the individual as he is at a particular point in time upon intellectual variables with reference to a normative or contrast population;
> 2. to predict the individual's status at later points in time;
> 3. to provide a behavioral profile of assets and deficits as a starting point for remedial programs;
> 4. to provide an objective means of checking progress of an individual or a group" (Clarke & Clarke, 1971, p. 1).

The first function, to describe the individual's intellectual functioning at a particular point in time, generally is coordinated with one or more of the remaining functions; i.e., present functioning is used either to predict later functioning, or to provide a behavioral profile upon which to base intervention, or as a pre-test measure against which to check progress or the lack of it at a later date.

If the aim is to predict later intellectual functioning (and for children who are eligible for adoption this is a function), there is reminder of Stott and Ball's documented admonishment:

> "Mental tests administered during the first year of the child's life are of no practical value in predicting later tested intelligence. Furfey and Muehlenbien (1932), for example, set out specifically to determine the predictive value of the Linfert-Hierholzer scale when it was administered during the first twelve months. They found <u>no</u> significant relation between the infant test scores and the Stanford-Binet scores obtained four years later....since the other published infant scales were very similar to the Linfert-Hierholzer in content and general make-up, their results called into question the predictive value of all infant mental tests" (Stott & Ball, 1965, p. 24).

In the forty-year interval between 1932 and 1972 continued attempts were made to relate infant developmental test scores to adolescent and adult standardized intelligence tests (McCall, Hogarty, & Hurlburt, 1972). Bayley offered a summary evaluation of these efforts:

> "It is now well established that test scores earned in the first year or two have relatively little predictive value (in contrast to tests at school age or later), <u>although they may have high validity</u>

as measures of the children's cognitive ability at that time" (underscore added - B.S.) (Bayley, 1970, p. 1174).

Reliability studies indicate that these low predictive correlations are not a function of poor test reliability. Likewise, efforts to determine if significant differences in predictability exist between sexes have tended to indicate that they do not, although the data does suggest that "Gesell predictions to later childhood IQ may be higher than for other infant tests, and that girls may be more predictable from the first year of life than boys, (nonetheless) long-term predictability from later in the infancy period appears to be comparable for the two sexes" (McCall, Hogarty, & Hurlburt, 1972, p. 732). Additional efforts to increase predictability have addressed attention to such variables as parents' socio-economic status, and the degree of vocalization in infancy. The resulting impression is that parents' social class is a moderately good predictor of IQ at CA 11, and the addition of an infant test score does not significantly increase predictability. Three studies have indicated that the amount of infant vocalization may have special salience in predicting the later mental performance of females, but not for males (McCall, Hogarty, & Hurlburt, 1972).

Despite these various considerations the conclusion obtains: during the first year of life there was poor prediction from infant tests to IQ in later childhood (McCall, Hogarty, & Hurlburt, 1972). The evolving question was "Why?" Answer was found in Piaget's and Gesell's work. Both held that as mental development proceeds there is qualitative change. Gesell viewed maturation as the mechanism which brought this about, whereas Piaget held that qualitative changes in cognitive functioning occur as a result of ongoing interaction between the individual and his environment. Through unique assessment methods he has demonstrated that cognitive development proceeds through a series of hierarchical stages, each evolving from the preceding one, but each qualitatively unique in its organization: i.e., different thought processes characterize the various stages of cognitive development. Measures which are appropriate for one stage are not appropriate for subsequent stages; you are not measuring the same thing at different stages. Predictability has not been Piaget's goal; instead, he has sought to observe and describe the process and progress of cognitive development. Piagetian descriptions of a specific individual's level of cognitive functioning are of particular use in planning intervention activities. Indeed, in their review and evaluation of infant mental tests, Stott and Ball (1965) conclude that

> "A promising approach to the construction of mental tests for early childhood might be along the line established by the work of Piaget.... (such a test would) express the levels of mental functioning for a broad band of abilities, each of which is possibly developing at a different rate, depending upon its genetic potentiality and environmental stimulation. Thus, as a diagnostic tool, it would be available for a differential analysis of the various aspects of a child's mental life" (p. 45).

Awareness of the need for a hierarchically sequenced scale of sensory motor development prompted Uzgiris and Hunt to use Piaget's Origins of Intelligence as a source for sequential behavior items which were easily observable and/or elicitable. The resulting Instrument for Assessing Infant Psychological Development (1966) provided a means for determining an individual's level of sensory motor development in six series of behavioral

schemata, and, in doing so, they met Woodward's (1971) criterion: an early measure which describes behavior in terms of "action" rather than "responses," an important criterion since it is a simple matter to watch an infant's action, but it is frequently difficult, if not impossible, to elicit his responses to test items.

As the mystique of the IQ is dispelled, and intelligence is no longer regarded as an "unchanging characteristic that governs nearly all of an individual's mental performance at every age (McCall, Hogarty, and Hurlburt, 1972), screening assessments are used increasingly as a basis for intervention rather than for prediction: i.e., they have contemporary utility in identifying early deficits. Although a variety of measures have established diagnostic value, when using any of them one should attend to the instruments' false positive rate (the percentage of subjects erroneously screened out as abnormal) and the false negative rate (the number of subjects allowed to pass as normal in spite of abnormality). As McCall, Hogarty, and Hurlburt (1972) note, a test may correctly identify 90% of the infants who are mentally deficient, and incorrectly classify as deficient only 15% of the normals. If these figures maintained in a random sample of 1000 infants, 45 of the 50 truly deficient ones would be correctly identified, but 142 of the normals would be incorrectly labelled as mentally deficient. When one remembers the anguish that parents experience when their child is diagnosed as mentally retarded there is realization that the standard error for any test should be accorded careful consideration.

Because infant measures assess sensory motor functioning, motor and other types of physical impairment can severely penalize performance, and in so doing can increase the rate of false positives. For this reason screening devices are needed which can circumvent the physical impairment and measure intact functioning. For the two- to six-year age range, Haeussermann's assessment "The Developmental Potential of Preschool Children" (1958) stands as the singular instrument to be devised to meet this need. At an earlier age, items on the Uzgiris-Hunt instrument, which do not require well-coordinated motor activity to assess memory and mental imagery, frequently have indicated intact functioning in these areas which was not manifest on other cognitive measures.

Another source of error is the acceptance of initial performance as true capacity. Clarke and Clarke (1971) hold that assessment is of limited value in the field of subnormality; "...in the severely subnormal there is a profound gap between psychological capacity and initial performance....(Nonetheless) assessment usually involves a one-trial measure on a particular variable, and hence scores are based on initial performance" (p. 4). Evidence is cited which indicates that when repeated trials are provided, the subnormal's initial assessment scores bear little or no relationship to final scores.

Also there is reminder that a major contributor to infant mental test performance may not be "mental" at all. As the young child is required to imitate the examiner, manipulate objects, and be verbally fluent, the true area of assessment may be social inhibition versus extroverted personality style (McCall, Hogarty, & Hurlburt, 1972).

When Stott and Ball (1965) sought information on the relative frequency with which various measures of early intellectual development were being used by individual clinicians, practicing psychologists, and researchers, as well

as their judgments on the effectiveness and limitations, the 15 tests which they reported as the most frequently used were:

1. Stanford-Binet
2. Goodenough Draw-A-Man
3. WISC
4. Cattell Infant Scale
5. Gesell Developmental Schedules
6. Ammons Picture Vocabulary Test
7. The Merrill-Palmer Scale
8. Columbia
9. Grace-Arthur Performance
10. Minnesota Pre-School Scale
11. Raven Matrices
12. Leiter International
13. Kuhlmann-Binet
14. California Pre-School
15. Griffith's Abilities of Babies Scale

The most frequently listed limitations were:

1. Poor validity
2. Manuals inadequate or difficult to use
3. Limited norms
4. Poor predictability
5. Insufficient diagnostic precision
6. Culturally outdated
7. Inadequate picture of child's functioning
8. Too subjective
9. Lacks theoretical rationale for dimensions measured

What is happening? Attempts are made to elicit responses to test items. The resulting successes and failures are summed into a test score which may be an IQ, and this two- or three-digit number describes an individual: e.g., his sub-score is 7, his IQ is 68. If this numerical description is to have any value in planning intervention programs it must be converted back into information on performance. Why this exercise in futility? Why not observe the individual's actions and use this information to locate him on a hierarchically sequenced scale of cognitive development? Comparison of his level of attainment with normative data would afford indices of deficits or delayed tempo of development. The level he currently occupies would be the starting zone for intervention activities.

False positives would be eliminated; knowledge of sequential development and repeated observation of his action would serve to insure correct location of his behavior on the scale. Programs involving foster grandparents as observers and trainers demonstrated successful application of this approach.

The post-program (rather than post-test) success of the intervention activities would be indicated by the child's progression or failure to progress to subsequent levels. Also sequential scales negate the importance of cut-off points between abnormal and normal. Instead of boundary lines, emphasis is on the level or stage achieved by the child in comparison to a

normative or control group, and on attempts which will assist him to proceed to the next level. Satisfactory techniques for developmental assessment now exist, and the task of training people to use them is not insurmountable.

The truly basic need in screening and assessment is to conduct research which will establish the relationship between a psychophysiological model and Piaget's model of cognitive development. From such effort one would hope to determine the influence of abnormal heart rate, irregular EEG, and other physical variables to progress or the lack of it through the various substages of sensory motor and preconceptual development. When this is achieved, current dualities will vanish.

To continue the earlier analogy, the priest may state, "There may be things wrong with the Church, but it's better than Purgatory"; and a developmental psychologist would acknowledge that there are things wrong with cognitive scales, but they are better than currently available alternatives.

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socio/emotional

QUASI-DEBATE PRO

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When I was assigned to the affirmative position concerning assessment and screening devices in the area of socio-emotional development, the only thing that made it possible for me to make sense of the assignment was that all the terms remained undefined. It was left wide open what we would mean by normalcy, deviancy, assessment or screening. Therefore, I shall choose very carefully among the possible affirmative statements. It would not be surprising if extraordinary harmony prevailed between my statements and those of the person taking the negative position, simply in terms of what I am not affirming.

For most of us a major difficulty in this area is related to some basic doubt as to whether we know in a substantive way what constitutes normal and abnormal socio-emotional development during the early years. I prefer the broader term personality development because it includes cognitive abilities for the role they play in every day adaptation, linked to many other developmental functions that emerge concurrently. The first positive assertion I shall make is that experienced people effectively make the kind of judgments which screening or assessment devices in this area are intended to perform. In other words, they are able to select from among groups of children those individuals whose development and functioning falls outside the range of normal expectation. The kind of people who are able to make such judgments are not limited to psychologists experienced with the phenomena of child behavior in ordinary life situations. They very much include early childhood educators. By saying that deviant children are selected in informal and pragmatic ways I do not say that a diagnosis or assessment of the nature and origin of deviation has been made - merely that those at risk, those showing deviant adaptation patterns, have been identified. Occasionally such apparent deviancy is found in extraordinarily gifted children as outstanding ability in some areas can generate adaptive difficulties in the socio-emotional realm. It has been mentioned here this morning that in other areas of development trained nonprofessionals have done better than physicians in screening criteria provided by a screening instrument. Nor should this be surprising. My second positive assertion is that deviant members of a population can be systematically identified, even when the etiology or the prognostic implications of the deviancy are not understood. It is possible to use thermometers without understanding the physical processes that underly the technique, and certainly intelligence tests were quite successful at a time when basic assumptions about the nature of intelligence were false - at least in terms of current understanding. The third positive assertion follows to the effect that: whenever collective empirical experience allows for effective practical judgments and discriminations, there is nothing to prevent us from translating this process into a systematic assessment procedure. In relation to socio-

emotional development I use the word assessment (not screening) advisedly. Screening I take to mean a relatively rapid procedure, intended to be used with large populations whereas by assessment I understand a more extensive procedure to be used only with selected populations who, for one reason or another, are thought to be at risk. (Or else, not relevant to this debate, when research requires assessment in order to compare different populations).

Even if we had the power to devise screening devices in this sense, which I doubt, I would strongly oppose the use of such procedures on a routine basis. Not only has massive screening of psychological characteristics done a good deal of harm, for instance the routine group intelligence testing in schools which labelled children in undesirable ways. But personality development and adaptation vary between sub-cultures and change with time. To build in something like a prescribed set of norms with respect to socio-emotional development would tend to deny and suppress the very flexibility and capacity for change which we prize and seek to safeguard.

Most assessment procedures in other areas of functioning, such as perception, cognition, or language, have used what one might call the experimental paradigm. Those expert in the field of tests and measurements seek to find one or a few criterion situations or highly standard tasks which correlate with the total area to be measured and therefore serve as a valid index. However, it is in the nature of the beast that adaptive processes, or personality development, manifests itself in the patterning, the directionality and the intensity of behavior organization over time and across situations. Presenting a child with an unfamiliar object on one occasion, or observing what he does when mother leaves the nursery on three occasions, tells you nothing about the child's responsiveness to novelty, or about the intensity of his attachment to the mother. For assessment purposes we will have to go where the data are, namely the behavior of young children in familiar situations.

The manner in which I think we can approach the task of using observational information for formal assessment purposes, may be suggested by brief reference to work we have begun to do. Though incomplete, the experience has convinced us that it is possible to be stringently systematic and quantitative, basing judgments on time-limited observational data obtained in ordinary life situations. In fact, I think that only a systematic and discriminating use of an aggregate of behavior episodes occurring in familiar situations over a range of time can provide the necessary information. A discussion of the behavior variables of greatest developmental relevance at different ages will have to be reserved for small group discussion. By way of an example, our research group has developed what we call a Personality Profile for Two Year Olds. The aim has been to specify behaviors observed in toddlers that are relevant to such dimensions as competence striving, curiosity, response to novelty, impulse control, anxiety proneness, imaginativeness and others. These definitions were made without any theoretical commitment, simply in terms of the delineation of behavioral responses to specified conditions which, for purposes of this rating scale, were coordinated to 'high' and 'low' positions on a continuum, depending upon the frequency distribution and range of observed occurrences. We found that although these terms (competence, curiosity, etc.) are loaded with all kinds of meaning that varies from one person to another - the absolute adherence to behavioral criteria led to excellent agreement among raters. Surprisingly, when 23 such variables were

applied to 4½ hours of observational material spread over a three-day period, agreement among different raters who held divergent views on child development, and included some who lacked a conceptual orientation, was excellent. It was possible to develop practical operational definitions for variables that describe adaptive and developmental characteristics in this age group. We happened to be concerned with differences among normal children but, by the same technique, it is of course possible to identify those children whose behavior falls beyond expected limits.

socio/ emotional

QUASI-DEBATE CON

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Performing basic research in the area of social and emotional development in infancy and early childhood is difficult. Interpreting these findings and developing screening and assessment measures to examine behaviors that have heretofore been the province of the clinician is even harder. This paper will briefly outline some of the difficulties encountered in designing screening devices, and finally will analyze some of the ethical problems to be encountered in both the design of measures and the implementation of mass screening.

At the present time there are few methods available which are useful in assessing social and emotional development during the first years of life. The Denver Developmental Screening Test (Frankenburg & Dodds, 1967) includes a section for evaluating Personal-Social development, Doll has developed the Vineland Social Maturity Scale (1965) and the Preschool Attainment Record (1967), and a number of problem check lists have been devised for behaviors ranging from autistic to zestful. However, there are problems around the use of these measures as part of a primary screening program. Some rely upon the ability of parents or caretakers to recall and report behaviors, others require skilled observers and/or standardized settings, and most take too long to administer. More importantly, most of these measures do not really examine social or emotional development. Rather, they assess the cognitive aspects of what can best be called social skills rather than the emotional and affective components of behavior.

A particular problem with many of these measures is the need to depend largely upon the recall and report of parents and others familiar with a given child. With regard to the use of such data, Yarrow (1963) states that "Stripped of all elaborations, mothers' interview responses represent self-descriptions by extremely ego-involved observers (p. 217)." She also notes that the typical interview requires many difficult discriminations be made by the respondent. Kohn and Carroll (1960) reported low agreement among family members interviewed about behavioral roles within the family. Father, mother and child agreed on supportive roles 46% of the time, with father and mother agreeing only 61% of the time. Additional data concerning the lack of reliability of maternal reports comes from a study by Wenar and Coulter (1962) who reinterviewed mothers concerning their child's development 3 to 6 years after an initial interview. Overall, 57% of the judgments were classified as the same. Over 16% of the responses represented significant differences between the interviews. While there was no tendency for the direction of change

to be either positive or negative, reliability was negatively correlated with the affective loading of the particular question. These studies lead one to question the usefulness of parental or teacher reports as a basis for social and emotional screening measures.

The examination of contemporary research approaches to the study of the development of social and emotional behavior provides an indication of the complexity of the variables with which we are dealing. Starting from a base of broad, general studies of behavior, efforts are becoming directed toward the study of specific behavioral systems. Louis Sander (1969) for example, has reported the presence of interactions between child and caretaker characteristics which appear during the neonatal period with respect to amount of crying, sleeping, and other behaviors. Similarly, William Condon and Louis Sander (1972) have applied methods of microkinesic analysis to behavior patterns in adult-infant interaction. They have found that infants move in precise, synchronous ways which are isomorphic with the articulatory structure of an adult speech stimulus.

Not only does the researcher have to consider the minute, elemental aspects of infant behavior, he has to interpret the meaning of behaviors exhibited by infants and young children. That the meaning of a behavior changes over time is demonstrated in a study by Michael Lewis (1967). He examined responses of 1-month-old infants to the withdrawal of their bottles during a feeding and the responses of the same infants at 12 months of age to being separated from their mothers and attractive toys by a barrier which allowed the maintenance of visual but prevented physical contact. The anticipated result that infants who cried in response to the frustration of bottle withdrawal would cry in the barrier situation was not found. Instead, infants who cried initially tried to overcome the barrier and those who passively accepted the bottle withdrawal cried at 12 months. Crying can be considered an adaptive response for a 1-month-old, but not for a 12-month-old. The meaning of the response shifted with development, but there was consistency across infants in the extent to which their responses over time were adaptive.

The examination of early behavior becomes even more confusing when it is realized that different responses can have the same meaning. The underlying emotional base for different behaviors can be the same. Taking responses to frustration as an example, infants may cry as was the case in the Lewis study, or they could avoid the situation entirely, turn away, go to sleep, or show auto-erotic behaviors such as rocking or thumbsucking.

The Lewis study is one example of the case in which a behavior classified as negative at one age may be related to positive behaviors at an older age. An additional example is a study by Jerome Kagan (1971) who found that 4-month-old girls who were rated as more irritable when placed in a strange crib were rated higher on creative play at 2 years than were less irritable girls. That this relationship was not present for boys adds a further confounding factor--the importance of considering sex differences in the development of assessment and screening measures.

On a broader scale, investigators such as Mary Ainsworth (Ainsworth, Bell, & Stayton, 1971; Stayton, Hogan & Ainsworth, 1971), Sibylle Escalona (1968, 1973), and Burton White (1972) have done much to expand our broad

knowledge about early social and emotional development through the use of detailed longitudinal observations. In addition to providing methods which might be modified to form a basis for screening and assessment measures, these studies have the potential for providing norms against which the behavioral development of individual infants can be evaluated. Ainsworth, Bell and Stayton found that 40% of a sample of "normal" 1-year-old infants displayed attachment behaviors in a strange situation which could be classified as normative while 20% displayed abnormal patterns. They make the interesting observation that this is approximately the percentage of the adult population that is estimated to have emotional problems.

Data such as Ainsworth's are encouraging in that they provide evidence upon which sequences of development and estimates of the incidence of abnormality can be based. In addition to performing laboratory research, however, the researcher should consider the development of screening measures and the problems they entail. This is difficult, but it is being done. One recent measure by Kuno Beller (1972) is a check list for examining the development of a variety of social and emotional behaviors at three month intervals from 3 to 36 months of age. In using this list you merely check whether or not a behavior is present and how far the child has progressed along each of the behavioral dimensions. Two of his content areas relate to autonomous achievement striving. With respect to body care, developmental behaviors range from feeding self with bits of food and holds bottle or cup, through initiates and completes body care activities, to the development of self control and delay of gratification. Along the dimension of mastery of the physical environment the scale goes from quiet, playful waking activity through knowing where things are kept to the development of a reflective approach to problem solving. Even with a scale such as this the problems of obtaining an accurate assessment without making detailed observations must be dealt with in order to implement screening on a large-scale basis.

At the present time, further steps toward the clarification of important social and emotional behaviors in early childhood are being made by a group of investigators chaired by Ira Gordon (1972a; 1972b). One major product of their efforts has been the development of a Matrix of Social-Emotional Variables. Relevant scales on this three-dimensional matrix deal with the environment, the particular behavioral dimension of importance, and the extent of behavioral expression. Classes of environmental variables are (a) self, (b) strange and familiar inanimate environment, (c) strange and familiar adult social environment, and (d) strange and familiar peer social environment. The seven behavioral dimensions within which social and emotional behaviors are classified are (a) exploring, (b) manipulating, (c) responding, (d) initiating, (e) avoiding, (f) pretending, and (g) evaluating. Each of these combinations of environment context and behavior is classified with respect to (a) neutrality, (b) hedonic tone (happy, sad), (c) range (expressiveness), (d) level of intensity, and (e) consistency. Work such as this will aid both in the development of appropriate screening measures through better conceptualization of important social and emotional variables, and through better definition of the range of behavior which can be classified as "normal."

This difficulty encountered in defining normal behavior brings us to the consideration of a problem unique to the area of social and emotional development. In general, in the areas of cognitive, language, and motor development

there is no real upper limit to acceptable behavior. An exceptionally intelligent or verbal child is not considered abnormal although, for statistical purposes, his performance may be two or three standard deviations above the mean. With social and emotional development there are both upper and lower bounds which must be examined as part of a screening program. Screening for the child who is too fearful, too attached, too assertive, or too aggressive compounds the problems encountered in the design of relevant measures.

This last point is related to a final, critical issue: the question of the ethics and values involved in screening and assessment of social and emotional deficiencies. At a fundamental level a trained clinician can tell you after detailed observation of a given child whether or not the child is socially and emotionally healthy. I believe we can develop suitable measures which will screen for variables of interest. The issue of values appears when we attempt to develop cut off points for the determination of abnormal functioning. For example, we might decide to screen out children as defective who show abnormally high affiliative tendencies combined with a low need for achievement. However, should we apply these criteria to a Chicano child whose parents have deliberately socialized for these attributes? How do we determine the relative importance of parental, subcultural, and societal values when they conflict? Indeed, can we speak of a consistent set of values for society at large with respect to social and emotional development? We must be able to answer these questions before we implement screening programs.

We may be more concerned with cultural differences than we are with cultural deficiencies. In particular, this issue is confounded with social class differences. Lesser, Fifer and Clark (1965) studied social class differences in cognitive abilities within four subcultural groups in the United States and found that cognitive abilities were similarly structured within but not between subcultures. Susan Gray (1971) has suggested that one solution to the dilemma of subcultural differences is to develop intervention programs that make a wide variety of options available to the individual. The poor have few options and those that represent optimistic choices may actually be harmful on a long-term basis as they are not realistically attainable (Rodman, 1963).

In summary, I have tried to raise some issues that are of importance in the design and implementation of screening and assessment programs for examining social and emotional development as well as to give a brief overview of the ways in which basic researchers are attempting to examine the course of social and emotional development. I hope that these issues and ideas will be a stimulus for further discussion.

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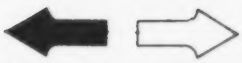

language

QUASI-DEBATE PRO

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I. GENERAL ISSUES

1. The ability to grow in language is the single most important developmental pathway available to infants and young children in the course of their perceptual, cognitive, and emotional growth.

2. There is hardly any such thing as a minor language problem. Any substantial degree of language dysfunction can be assumed to be either the cause or the effect of seriously disruptive developmental disability.

3. It is probable that the great preponderance of language development hazards in infancy and early childhood can be assigned to the following four categories:

a. auditory impairment
b. central integrative dysfunction
c. inadequate environmental support
d. peripheral expressive impairment

4. The primary task of screening is to identify children who manifest a high probability of significant developmental deficits in any of these categories. The task for assessment is to identify as specifically as possible the nature and degree of handicap and the domains of residual competence in order that assistive intervention may be mobilized to attempt to overcome the disability.

Perhaps the greatest present need in assessment is to overcome past tendencies to concentrate too much attention upon specifying only the disabilities. With greater effort expended at identifying what impaired children can do instead of what they cannot do, greater progress could be made in helping retarded and damaged children employ a greater scope of their potential in learning to meet the real life demands of adaptive experience. For example, great progress is now being made with new techniques in measuring specific visual and acoustic-linguistic capabilities of severely retarded post-rubella children generally regarded as deaf and blind. This shift in emphasis from the negative, decremental view of assessment to a positive, incremental recognition of residual competencies offers a more meaningful basis for effective intervention.

5. Deficits of auditory acuity are the most readily identified and the most heavily emphasized domain of language impairment. However, deafness is one of the less significant vectors of language disability.

6. Existing techniques are reasonably adequate for screening, assessing, and assisting children whose auditory and expressive disabilities are in the mild and moderate range. This is also generally true for peripheral expressive impairments. Society's task in these cases is the expensive but relatively uncomplicated one of mobilizing existing skills in sufficiently large supply and with sufficient personnel to do a job that can be done in terms of presently known methods.

7. Central integrative dysfunction, inadequate environmental support for language development, and severe auditory impairment in its usual context of multiple handicap--these conditions present an altogether different picture. Existing knowledge and techniques are substantially inadequate to meet the complexities of the screening and assessment problems they entail. Present audiological evaluation procedures, which are essentially acoustical in nature, are inadequate for assessing language development disorders based on central integrative dysfunctions and environmental inadequacies.

8. The benign consequences of early intervention may have to be regarded as speculative, even in seemingly uncomplicated cases of "simple" deafness treated with early application of hearing aids. Reports of success are largely anecdotal. Without minimizing the importance of single cases in which early identification of hearing loss and early application of hearing aids leads to language learning progress, there are large numbers of cases with less happy outcomes. It is not uncommon in schools for the deaf to find many children who have been wearing hearing aids since infancy for whom speech has little or no meaning. Electronic amplification to overcome deficits of auditory sensitivity seems to have little bearing on the limited progress these children make in their use of spoken language. These are children whose language learning deficits stem from more intricate information processing problems than just the loss of hearing.

9. Current theory, increasingly supported by confirmatory evidence, strongly suggests that a continuum of language and related information-processing central dysfunctions underlies a broad spectrum of developmental disabilities in the psychological sphere. Learning disabilities are at the mild to moderate end of this continuum, while more severely involved children manifest the symptom patterns associated with schizophrenia and autism. On this continuum, even "mild" can be pretty bad. In our school-oriented society the consequences of learning disabilities are generally highly disruptive to the life of the child and to his family.

10. Within this continuum there are many categories of involvements associated with disorders of language development in which it is hard to distinguish causes and effects. Children with language deficits are frequently assigned to intervention programs on the broad basis of retardation, learning disabilities, sensory impairments, emotional disorders, neurological impairments, and behavioral disturbance in the absence of clearly defined pathologies, diagnoses, and prognoses.

11. This chaotic situation is not necessarily due to professional incompetence, but to the generally primitive state of the art of assessing language dysfunctions. For example, I know of no existing, validated instrument by which it is possible to make a reasonably clean differentiation between central integrative dysfunction, low adaptive intelligence, and

inadequate environmental support for language learning in the cases of children below the age of five whose language development progress is disappointing. This differentiation requires the personal judgments of a skilled diagnostician whose judgments are not necessarily reducible to operational statements. Once this differentiation is established, the manner of treating children in the various categories is enormously different--or at least it should be.

12. In its more subtle forms, language dysfunction is probably far more widespread in the general population of children than is commonly recognized. In one recent study in an affluent suburban primary school, 25% of a randomly selected population, Kindergarten through second grade, showed a previously unrecognized anomaly of language perception--which correlated very highly with the incidence of reading disability. Comparable results have been found in other studies involving hundreds of suburban children. It is probable that the incidence of these subtle language anomalies is even higher in less favored socio-economic communities.

13. Further study of this provocative issue might well reveal that dysfunctional language growth lies at the root of many disabilities of academic, interpersonal, and social behavioral development that are presently ascribed to other causes. If this proves to be the case, then the issues of language adaptation will be seen to have more far reaching significance than has thus far been realized.

II. PRACTICAL PROBLEMS

1. The relatively "simple" sensory deficits of hearing and visual acuity are probably the only disabilities associated with language disorders that are reasonably well-defined in terms of established instruments for screening and assessment. However, important as they are, audiometry and optometry are helpful in evaluating only the first stage sensory impediments to effective central information processing operations in the central nervous system upon which language development depends. Only a small fraction of children manifesting significant language problems suffer deficits of hearing acuity. Hence, these well-defined evaluation procedures apply to only a limited number of the infants and young children for whom effective identification and assessment is needed.

2. Language inventories such as Honig's Early Language Assessment Scale provide useful information on external aspects of language performance and gross behavior related to auditory-vocal-linguistic activity. However, these observational inventories are quite limited in their assessment of more covert capabilities of underlying language competence. Also, they are especially vulnerable to false negative identifications. They tend to attribute deficit capability to young children who have difficulty mobilizing their full competence under the stress of test, school room, or intra-family tension. At the other extreme, tending toward false positives, the less severe language dysfunctions of late infancy and early childhood, which may prove extremely disruptive to adequate progress in school, are often masked by adequate patterns of socialization in daily life. In family environments which present limited linguistic demands and limited language learning support, children's real language learning deficits may go unrecognized in the absence of conspicuous behavior problems.

3. Generally available instruments for assessing central processing of visual and auditory information associated with language development are extraordinarily primitive in terms of the complexity of the psychological functions they are designed to evaluate.

For example, in the visual domain, all standard tests of visual perception rely essentially upon static images printed upon flat surfaces. Yet every first-year graduate student in psychology knows that the real phenomena of visual perception involve the high-speed integration of sensory inputs from highly dynamic visual fields in three dimensional space.

Likewise, most methods for assessing language performance employ test items based upon single words, single phrases, or single sentences. Yet it is apparent that the real work of processing language involves much larger units of information. In order to be linguistically competent, children must be able to learn to decode and encode meaning in terms of extended streams of speech if they are to keep pace with the growth patterns that are expected of them in the family, in the classroom, and on the playground. These are the characteristics of language competence that must be assessed when it is necessary to assist the growth of children who manifestly do not keep pace with expected growth.

4. New methods for improving the assessment of language disabilities and residual language competence in infants and young children with disabilities are in various stages of development in a number of laboratories in this country and abroad. At present, as far as I know, none of these methods--including my own--is sufficiently validated by extensive experience to be regarded as ready for standard operational deployment on a wide scale such as is contemplated in the planning for this conference. Insofar as it may be necessary to include language assessment at early ages in a wide scale program in the near-term future, existing documented scales such as the Illinois Test of Psycholinguistic Abilities, or the emergent evaluation techniques, should be employed only with caution and full awareness of their limitations.

5. Major support should be assigned to accelerating the development of the emergent evaluation methods which offer substantial prospects for improving assessment of the central integrative dysfunctions and the environmentally induced language disabilities that affect such large numbers of children.

6. It should be recognized that assessment of language capabilities at a level of sophistication commensurate with the complexity of language processes will probably pass through a stage of technical development in which it is very costly. There are healthy long-term prospects for developing highly efficient, automated evaluation procedures for examining critical constituents of language competence and performance with considerable efficiency and economy with large numbers of children. As of now, means for attaining this objective are not clearly in sight. But there is the promise that it can be done. For the foreseeable future, meaningful, in-depth procedures for evaluating the diffuse, multi-level processes of language organization cannot be implemented on the model of simple, one-shot test sessions that produce a single score or set of scores. It is still necessary to view assessment of an individual child as an investigative procedure that seeks to characterize complex competencies across a wide range of acoustic-linguistic

variables at several points in time in repeated test sessions.

7. Let me cite two examples. I recently read a report of an emergent language assessment procedure for use with autistic children in which a three-year-old boy was given 6,370 trials over 91 sessions in order to learn if he could combine two lexical units which he had little difficulty identifying when they were presented singly.

In my own laboratory, we are now arranging with several institutions in Connecticut to conduct automated PLAY-TEST evaluations of certain critical functions of receptive language capability in severely retarded children. We will conduct approximately 1200 evaluation sessions at a direct cost of approximately $20,000, a figure which does not even include such critical costs as depreciation of the instruments and several salaries. This comes to more than $15 per test session--and some children may require 10 or more sessions if we are to get the information needed to establish the boundary conditions of their basic receptive language integrity.

I may be wrong, but in my judgment procedures this expensive are not yet suitable for wide scale application--even if the information is important and not yet attainable by truly economical means.

8. I would like to close on both a downbeat and an upbeat note. On the downbeat, psychologists and behavioral scientists should recognize that our past record in screening, assessing, and evaluating people is not particularly good. While we have a number of very substantial accomplishments to our credit, we also have made some extremely serious blunders. The most serious of these blunders have been those by which we have misclassified people to negative status and negative roles on the basis of tests that measured the wrong dimensions. Looking back over the last 50 years of the intelligence testing movement, it would be difficult to estimate how many hundreds of thousands or millions of children have been deprived of developmental opportunities because psychological technology polluted the atmosphere of valid linguistic and subcultural differences. We now see that mistaken applications of our technology and just plain sloppy workmanship at high executive levels in the corridors of power have done a great deal of personal and social mischief. If the behavioral science establishment is going to begin to screen, assess, and classify at even younger age levels than in the past, we must take exquisite pains to be certain that the quality of our executive decisions and technical performance in the future is at a much higher level than has often prevailed in the past.

On the upbeat side, we can look with reasonable confidence to a future in which our society at last appears willing to increase substantially its serious, informed concerned for the well-being of children who must start out in life with disabilities which jeopardize their prospects for normal growth and development. We are at the outset of a new period of social evolution when new patterns of care and concern will be matched by new societal institutions through which this care and concern will be transmitted to those who require it. Perceptive and expressive language are the principal means of human communication. It is appropriate that great energy, substantial resources, and special concern be devoted to the search for better methods for understanding the needs and assisting the growth of children who must overcome unusual liabilities in their efforts to join the human community through the medium of language.

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QUASI-DEBATE CON

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I have spent most of my professional life being affirmative about this; but as I began to work with it, I had somewhat the same experience as Dr. Friedlander had. There are a lot of problems and a lot of weaknesses, and I think these are the things we need to point out anyway.

I agree entirely with Dr. Friedlander concerning the very great difficulty of assessing language problems which may be due to central processing, if we want to call it that. He did such a good job with this, I'll pass it; but I would like to say just a little bit about assessing peripheral hearing. I hesitate to do this because there are a number of audiologists in the audience and I'm not one, but I have been briefed by a very good audiologist on my staff. I know he is good because he had his post-doctoral year in Audiology at Johns Hopkins under Bill Hardy, and Bill is in the audience and I'm sure he would verify that this is good training.

There has been a great deal of controversy develop around the screening of peripheral hearing in newborns and infants. Marion Downs[1], who is also in the audience, started this thing off some years ago when she did some screening in newborn nurseries. For a long time audiologists have worked at this, but there have been some serious problems develop. Young[2] lists three problems that have been most serious: 1) there has been very little agreement on what constitutes a response from a newborn; 2) there have been too many false-negatives; and 3) there is too much disagreement on follow-up. How is the follow-up done, where does the patient go, who does it, etc. Young suggests that perhaps the nursery isn't the place to start our auditory screening, but he does think that from about three months on we can do a pretty good job.

I would like to point out just a number of the very practical problems that can enter into this. It takes accurate experienced observation to tell when eye-blink, body startle, arousal, or cessation of activity, head turning, and so on, are occasioned by auditory stimuli. These would appear to be simple things to recognize but they're not really, because the infant is doing a lot of this anyway. It also takes accurately presented stimuli, calibrated signals, and a quiet testing environment, usually sound-treated. It usually requires two persons to do the job, and at least one of these needs to be an experienced, skilled tester. These conditions are true until the child can be conditioned to pure tone audiometry at the age of about four or later, depending on the child. The entire process is very time-consuming, it does take some special equipment, and above all it takes some trained personnel to do it. Now if screening is to be done on a mass basis, who is to do it? Where is it to be done? How are the personnel to be trained?

Screening identifies only suspects. Referral and follow-up are very difficult and often inadequate because of several reasons. Referral involves the next step -- a thorough assessment, and the assessment of the infant and

young child is still pretty subjective. The techniques are risky and at best we can assess only severe losses with any great certainty. Minor losses which cause so much speech and language trouble, losses at both frequency extremes, and other selective hearing losses, are frequently not discovered.

The high-risk approach to screening, which has been rather widely used and probably more effectively used in auditory screening than most other developmental areas, has been good, but this hasn't been well done[3]. To date, however, this is the most promising approach to auditory screening of infants.

So much for hearing screening; what about speech and language? For many years we were quite unconcerned about speech and language development until the child was 2½ or 3 years of age, because he "isn't talking yet." But in recent years a number of fairly effective screening instruments have been developed for younger children. We have used a MANUAL FOR THE EVALUATION OF SPEECH, LANGUAGE AND HEARING for about ten years at the University of Oregon Medical School, Crippled Children's Division, and have had some good success with it. The DENVER DEVELOPMENTAL SCREENING TEST[4] is being widely used now, and Boyd's CCD DEVELOPMENTAL PROGRESS SCALE[5] is proving to be very effective. Both of these have communication skills screening sections among a number of others. These are pretty good instruments, but the problems with them are in the way they are used. There are a number of weaknesses.

Screening examinations should sample several dimensions of communication skills; not only verbal expression but verbal comprehension as well; not only production of sound units, but word units also; and finally syntax (grammatical structure) and semantics (meaning content). Screening instruments in use can sample these areas fairly well if they are well used, if they are used by people who are trained to do it. I don't mean four years of training, but some kind of thorough orientation to their use.

If screening is to be done on a mass basis, it is going to have to be done by nonspecialists; by this I mean people who are not Speech Pathologists or Audiologists. Where are we to get these people? Dr. Friedlander points out some of the difficulties with some of the instruments that we have. I agree with him, but I still feel we can do a pretty good job of screening, if we can use trained screeners. Dr. Boyd found the other day that a medical student whom we have in training had handed the CCD Scale to the mother to be checked while he went on with his physical examination. Well, it isn't that kind of a scale; and none of them are. Another problem, as Dr. Starr pointed out, is that there is too much reliance on parents' answers. You just can't trust parents' answers without much further probing, yet we do. Another difficulty is that there is too small a sample of behavior in a limited time and in the limited situation where the screening has to be done. Another problem is that the screener doesn't know what he is hearing, especially in the area of articulation disorders. An Orthodontist sent us a patient not long ago because "he had trouble with his th sound." He had a beautiful th; he was just using it in place of an s, such as in "thoup" and "thithter" and "tho on". This is an easy error to make if you don't have a little training in phonetics. Another problem is that the screener frequently doesn't know the landmarks of speech and language development, so he expects more or less than he is getting.

Finally, if we can do a good job of screening, which I think we must do, this calls then for referral, which calls for more full scale assessment, and there are a few problems here. Who is going to do it? There are not enough specialists to do good assessments. Where are they located? Are they where we need them? Are they adequately trained? (I am sorry to say that many Speech Clinicians that I know are not trained to do assessments of very young infants and children. They can handle most school-age speech problems, but they can't do the job that we are talking about. Many people working in clinics don't do this because they don't have the experience or the training.) After the assessment is done, who is going to do the treatment? Where is the therapy going to be done? We are going to turn up a lot more problems than we have now. Do we have the people to do it? If not, how can we get them?

If time allowed we could list more such problems, but perhaps these will stimulate further discussion.

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⇦ ⇨ recommendations

A SYNTHESIS OF RECOMMENDATIONS FROM SMALL WORK GROUPS

1. Any screening and assessment program should take into account all factors of human life and development. Therefore, the context in which screening is accomplished and the ways in which the results and processes are related to the life of the child and his interaction with the community are important. Similarly, the rights of children and their families to participate in decision-making processes should be respected. Screening and assessment should be seen as preliminary stages to a general program of prevention and remediation -- they should be service, not research, oriented. Screening should identify conditions which interfere or likely will interfere with effective functioning and for which there are remedial, control, or prevention procedures available. Priority should be given to conditions of highest incidence and/or greatest severity.

2. Screening and assessment should be seen as a dynamic process that continuously surveys children in the course of their maturation and development. It begins with a series of steps that preliminarily identify conditions and behaviors which vary from more advantageous forms of human development. Screening is a tentative selection of groups of vulnerable individuals and is seen as differentiated from assessment and diagnosis. These latter terms are a more definitive identification of the problem areas. Screening is not a labeling process but a pragmatic process leading to the discovery of what treatment will work with a child.

3. Screening should be viewed as a continuous process beginning at preconception and repeated during the course of the preschool and school years. The purpose of repeated screening at regular intervals is to identify conditions that (a) might have been missed originally, (b) might present themselves at a later age, and (c) might improve with the tincture of time and should be removed from surveillance to protect those individuals who have recovered successfully from negative influences or those who have been erroneously placed in the high risk or disability categories. These in high-risk categories require more frequent monitoring whereas the nonhigh-risk infants may be satisfactorily checked at regular immunization times about four times during first year, with various procedures tailored for a given age.

4. Screening without intervention and eventual program planning is futile and may be even detrimental. Positive findings must be combined with careful counseling with the parents in order to maintain or even improve parent-child relationships. The screening certainly must not be painful to the child nor harmful to the family.

5. It is recognized that there are numbers of tests, scales, and related procedures that are generally accepted which can be applied in all categories of human functioning (see companion Monograph and Background Papers for more detailed description of these). Due to the relatively poorer predictive power of early screening in the cognitive, social, and emotional spheres, mass screening in these areas is contingent upon improved techniques.

6. The simplicity of these initial screening devices should enable the training and utilization of a wide variety of personnel to provide the initial information. Training should be standardized and credentialled, e.g., child development associate with certificate of competency from training agency such as a junior college and/or U.A.F. Parents should become involved in the identification process; paraprofessionals can be trained to train parents to be better observers and reporters on their child's development. This would lead to a design for delivery of services that would require that a progression through various levels of expertise and experience be followed to confirm and clarify the nature of the disability.

7. At each point in the process a coordinator or coordinating agency must be provided to insure integration of findings and provisions for services. Already existing resources should be encouraged to recognize the need and use of screening procedures and incorporate them into their services. The national network of University Affiliated Facilities is a logical mechanism for providing training to all levels of paraprofessionals and professionals and for coordinating a national screening and assessment program; in cooperation with the mental retardation research centers, provision for economical biochemical screening for esoteric conditions such as various inborn errors of metabolism and other congenital disorders can be arranged and cut across state boundaries. Local health departments could provide or recruit necessary manpower.

8. A comprehensive screening and assessment system should resolve problems noted around the whole child and his needs. This requires improved utilization of existing services and professionals. Similarly, it implies total parental and community education concerning human development, disabilities, and the availability and/or non-availability of services; high school courses should be developed and implemented for this purpose.

9. The organization and institution of a fully developed program must have sufficient lead time for acquisition and training of personnel and allocation of adequate funds necessary for its success.

10. An improved system of data compilation should be developed to insure that evaluation and treatment facilities have full knowledge of the past course of a child's development, of all previous test findings, and information about the results of any action taken. Provision should be made for keeping the data confidential. Consider use of Internal Revenue Service or Social Security data collection systems with national records center to help follow transient families. Data must be easily recorded, efficiently retrieved, and properly suppressed to avoid pernicious effects of labeling.

11. A study of the cost-benefits of early identification and intervention programs as contrasted to a late identification and intervention system should be made. The concept of parsimony should be pervasive in the sense of optimum yield for minimum cost to the ultimate welfare of society and the child. The same study should be designed for and conducted in a given community and be followed by a cost-benefit analysis in which screening on the basis of high risk criteria and screening on the basis of disabilities categories are contrasted. This would help to determine which conditions are optimally identified in their asymptomatic stages and can more effectively be treated at that point.

12. Improved techniques should be developed for encouraging participation by and for gaining acceptance of groups which have been designated as "hard-to-reach." Mobile units such as used in national polio vaccination or hearing screening programs should be one effective approach; training of homemaking counselors in County Extension services to do and demonstrate developmental screening in rural, sparcely-settled areas is another possibility. Care must be taken to adequately involve low SES and minority ethnic groups in the planning of a comprehensive screening system and that cultural differences not be interpreted as high-risk factors nor should screening in any way discriminate against any subculture. In a pluralistic society there are especially wide differences with regard to what constitutes a life of quality and a screening system must not directly or subtly impose chauvinistic norms on others.

13. Current research findings should be applied to a deliberate working base in screening and assessment. It was agreed that substantial information exists that is not, or in its present form cannot be, applied to concrete work situations. This transfer of information was seen as crucial.

14. Survey and compile existing legislation which now is supportive of such early screening and assessment endeavors. Identify appropriate consumer pressure groups to increase percentage of national and local expenditures to eventually insure that <u>every</u> child receives benefits of routine early screening and assessment for developmental disabilities.

summary

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I am frequently called upon to summarize meetings, often even when I am unencumbered by too much factual knowledge, as may well be the case today. I assume that I have earned this honor because I have demonstrated a high degree of tolerance for uncertainty. This tolerance is essential because conference summaries must be prepared at the last moment and must have some relationship to the conference content itself.

Before proceeding further, I would like to express appreciation to several individuals who were responsible for the planning and the conduct of the meetings. I am sure that I speak for all of us when I express gratitude to Mrs. Jeannette Rockefeller and Dr. Julius Richmond, to the sponsoring agencies, to the organizing committee, to Dr. John Meier, to Mr. Tadashi Mayeda, and to Dr. Allen Crocker and his staff. In every respect, from content to comfort, this has been a most outstanding meeting.

Now as to my summary, I have two choices. I could try to restate that which you heard in the plenary sessions, in the workshops and from the recorders, but this approach would be repetitious and futile. You have listened to what has been said and at some time in the future you will have an opportunity to refresh your memory by reading the proceedings. In lieu, I will first comment on the "process" of the conference as I observed it, then make some general remarks, and make some suggestions aimed primarily toward the President's Committee on Mental Retardation. On the one hand, I share the anxiety of those who expressed concern over the probabilities that our recommendations would not be implemented; but on the other hand, as a former member of the President's Committee on Mental Retardation and currently as one of its consultants, I feel very confident that members of the Committee will listen carefully to what we have to say and will take to heart every recommendation we make.

First, as to the conference process itself, may I state that I cannot recall any other meeting of this type which was better than this one. The state-of-the-art document entitled Screening and Assessment of Young Children at Developmental Risk, which John Meier prepared, is one of the best in the field and in my judgment will be regarded as a text book on the subject. I was tremendously impressed with the choice of invitees. It is extremely difficult to select individuals for this purpose, particularly when one is confronted with a fixed limit in numbers. Let me assure you that it was done with great care. Unfortunately, many who could not attend lost a significant opportunity to learn. We also lost because we could not profit from their contributions.

I was equally impressed with the Friday morning presentations, each was excellent in its own right. I tried to attend all the workshops but time did

not permit me to do so. Those which I visited I found to be goal-directed and hard at work. I am sure the others were of equal quality. I cannot select any one of them for special remarks. I found that after the usual open discussions in which everyone participated, the groups rapidly settled down trying to identify their most important recommendations, which when collated will provide the President's Committee and the other involved federal agencies with a schedule for progress during the next decade. The recorders, as you heard, did a most admirable job in summarizing the gist of the workshop debates.

Now, some subjective observations and comments on my part. In collecting my data I followed my usual custom. I listened carefully during the official sessions but paid maximum attention to the conversations which went on Thursday night and the next two evenings in the Minuteman Room. I learned a long time ago that you get the most candid opinions and the greatest amount of insight at informal gatherings, particularly during cocktail hours. These were unusual experiences because the topic of most, if not all, conversations remained the subject of the conference. I heard few jokes but very much about "screening of children." The conference indeed stands out in my mind in this respect.

Let me report to you some of the recurrent notions I heard time and again. We have not resolved all of the issues! This is a theme that came through equally clearly in the workshops. For example, I found no unanimity concerning the definitions of "screening," "identification" and "assessment," nor pertaining to our concepts on the relationship of these three processes. Nor did I find agreement on the target population. Should screening, identification or assessment be restricted to the 0-5 year old children as the state-of-the-art manual says, or should we include in our plans prenatal screening? Or should we be thinking of intermittent lifelong screening? Should we restrict screening to those considered to be at high risk, or should screening involve the total population of a specified or unspecified age? What are we to screen for, or what should our assessment be aimed toward? Are we concerned with definable conditions only or with aberrations of a more general nature?

I often heard comments of the following nature: "Screening does not exist in isolation. It is to be viewed as being strongly related to prevention, intervention, and treatment." "Screening must be related to all systems of care and concern. It cannot be seen as existing independently of such major social systems as health care, education, welfare, etc. We must somehow link these systems around the issue of screening." This is no easy task. It would require, for example, the linking of the educational and health systems which in itself is a monumental task. As I have observed the issues over more than two decades, education functions primarily in the public, and health care in the private domain. Each has its own tradition, its own hierarchy, even its own bureaucracy.

"For the obvious, like the profoundly retarded, screening is irrelevant. Its importance lies in its benefits for the less severely involved, but that is where the job becomes more difficult if not impossible." I was, however, strongly impressed by many comments of those who seemed ready, willing and able to tackle the more complex process. They certainly outnumbered those who were concerned with the current difficulties of this task. "Screening

must be interdisciplinary. How can we expect interdisciplinary programs when we even encounter difficulties in communication across disciplinary lines in our workshops?" Yet I for one observed substantial ease and efficiency in interdisciplinary communications in each of the workshops which I attended. I do not think this ought to be a difficult problem to solve, particularly if we prove to be willing to surrender some of our parochial prerogatives.

"What are the norms and what are the standards to be used in a screening, identification and assessment program?" I was intrigued as I listened to several of our colleagues in the behavioral sciences who readily accepted norms expressed in biomedical terms at face value, but were quite leery about the "hardness" of norms when these pertained to such dimensions as personality, emotional maturity and the like. As a physician, I can confess to you that many biomedical norms are not any firmer than those which originate in the behavioral realm. Be this as it may, I gleaned from many comments that we have sufficient technology to initiate screening programs. Most discussions centered not on the question whether we have adequate tests but rather on the issue which test is the best or most appropriate.

"Our manpower is totally insufficient. Our search for a national program is futile, therefore." I agree that we do not have enough pediatricians, developmental psychologists, or people in any of the relevant disciplines. On the other hand, I heard the majority of my informal sample express a much more optimistic outlook. "Yes, we can create the manpower if we get rid of our idiosyncratic professional approaches to the issues and develop new classes of workers, each qualified to do a meaningful task and each trained sufficiently but not grossly excessively."

A set of contradictory statements usually went as follows: "Screening is important, essential and we must do it" or "Screening is expensive and we cannot afford it." I agree with those who voiced the first view, and believe that we must start a major program and cannot afford to do otherwise. To support my argument, I did some arithmetic late last night.

I tried to approach the cost of a national program from three perspectives. First, I attempted to assign the cost figure to screening on a per child basis. We know that certain biochemical screenings cost pennies only. I also feel confident in assuming that the overwhelming majority of our children are well developed and healthy, so that they can be screened into the normal population at a cost of relatively few dollars. A similar cost figure would also apply to the small number of individuals who are obviously and grossly impaired. The highest cost pertains to those individuals who are on the borderline between normalcy and impairment and whose underlying problems are complex. Here the price may well be in the multi-hundred dollar range.

I finally settled on an average of $100, which I judge to be a high cost rather than low. Our annual national birth cohort is around three million babies. Multiplying this figure by $100, I estimate the annual cost at $300 million per year. At face value this might be a frightening amount, but when related to some other figures the perspective becomes different. Even if one assigned the total cost of screening to the health care system, it becomes obvious that $300 million represents less than one-half of 1% of our national expenditures for health care. In addition, screening, as conceptualized at this conference, is as important from the viewpoint of education as from the

viewpoint of health care. When the national expenditures for education are taken into account in our calculations, the cost of screening becomes less than one-quarter of 1% per annum.

I then tried to arrive rapidly at some estimate of our cost involved in the development of a self-supporting tax-paying and generally contributing citizen. This process starts at the time of conception and includes pre-natal care, delivery, health care, child-rearing and education, among others. The process is usually completed somewhere around the 18th to 20th life year and certainly costs at least $20,000. If one relates the cost of screening, i.e., $100 to this figure, we arrive, again, at the same one-half of 1% which is a pittance if it can prevent lifelong tragedies or improve the lives of our population.

Finally the following approach occurred to me. It is generally advocated by the health system that everyone ought to have an annual physical examination. If our admonition is heeded by our 200 million citizens, and assuming that the cost of a good annual examination is also $100, we derive that the cost of annual physicals would be at the level of $20 billion, that is to say, we would expend between 25-30% of our gross national health cost on this preventive measure. Comparing the $300 million with $20 billion, again, puts the cost of screening into a practical perspective. I concluded, as a consequence, that even though the expense of screening may seem high, if it is compared with other expenditures the amount certainly is not prohibitive.

In my judgment the future of any aggregation of people of any nation or society depends upon the quality of its reproduction, its children, and its succeeding generations. This fact, if not fully acknowledged as yet, will soon become recognized. Unfortunately, in the past we were more child-oriented in oratory than in action; however, I see rapid change forthcoming.

One comment on priorities. In my judgment there is an overriding unity to mankind which is independent of race, color, creed or socio-economic status. If you agree with me on this principle, it should be self-evident that if any constraints force us to select a segment of our population for screening, it ought to be that which needs most help or is at a high risk. Vis-a-vis mental retardation, I have often said that in our otherwise well endowed society there is a segment, the members of which, generation after generation, inherit not the genes but the environmental circumstances which predispose them to, and in fact in many instances create, the phenomenon we describe as socio-cultural retardation. This vicious cycle must and can be broken. The answers lie in a number of social systems which range from health to economics. But once this problem is resolved, the cost of screening can be halved or even quartered. Screening can improve the quality of life and if we must select a population group as our first target, it ought to be the one which has, currently, the poorest quality of life.

If I missed anything in this conference, it pertains to a clearer focus upon the ethical implications of screening procedures themselves. It was brought up, I believe, in regard to the trait carriers of phenylketonuria. But let me add a few other troublesome questions. If screening shall include karyotyping, what will we do when an XYY infant is identified? What shall be our posture when we notice that treatment resources do not match the needs identified by screening? How should we weigh the pitfalls of labeling against

the benefits of intervention? I wish that at least one of our workshops had decided to spend a little more time on considering these and other ethical issues. Maybe these shortcomings can be corrected at a next conference.

This, then, brings me to some suggestions addressed particularly to the President's Committee on Mental Retardation. I believe the reports will require some editorialization and some combinations of the many suggestions. I know this can and will be done, and I feel that then the report ought to be widely distributed. I also recommend that we continue our efforts in several directions. In my judgment another conference is needed. I suggest that the next one, whether of a national or regional nature, be more focused, that is, the planning of the conference take into consideration not only the distillate of this conference, but also develop one, two or three de facto operational models for screening. One of these may well be a model currently in operation in some locale; the others could be conceptualized models but specified to the extent that they can be viewed as practical examples. The conference could then settle down and evolve at least one final model to be implemented.

Such a finalized model would, in my judgment, still require field testing. I do not believe that a national program could or should be implemented throughout the country without field testing and evaluation. Such limited experimentation would produce information on the sensitivity and the specificity of the screening tests used; on the acceptance or nonacceptance of the program by the target population; on costs, benefits, efficiency, and manpower needs. An ultimate national program must be adaptable to local circumstances and must find equal acceptance among the economically endowed and the economically disadvantaged. I propose that after adequate field testing, a national screening program can become a reality.

Let me close by stating that you have contributed greatly to the development of many excellent ideas but you have also acquired a significant responsibility for the future. The continuation of this new thrust rests as much in your hands as in the hands of the President's Committee. Upon your continued efforts depend many benefits of future generations of children. I am comfortable that this trust is in good hands.

closing

Mrs. Jeannette Rockefeller:

Thank you, Dr. Richmond. First, I believe that all of you will be interested to know that we hope to have the monograph completed within approximately sixty days, with the full proceedings of the Conference finished in ninety days.

As soon as the proceedings are in final form, the President's Committee on Mental Retardation will officially present the report to President Nixon. We are confident of his deep interest and his support, as he has gone on record as hoping to see the incidence of Mental Retardation reduced by one-third by the end of the present century.

Initially, this date seemed rather far away to me until I realized that the turn of the century is only twenty-eight years from now. Suddenly it became clear that all of us have a great deal to do in the next twenty-eight years if we are to see the very commendable goal of the President attained.

In closing, I would like to stress one point which has concerned all of us, and that is implementation in carrying forward the work that has been begun here. As both Dr. John Meier and Dr. George Tarjan have pointed out, this is a terribly important Conference but it is only a beginning. In considering and planning for next steps, we have been discussing the possibility of a series of Regional Conferences. As many of you have noted, such future meetings should incorporate far more diverse representation, in the way of reaching out for more interested groups, broader ethnic representation, and wider public involvement.

I am particularly concerned that individual states be given strong attention in the development of future Conferences. We would hope to involve state officials and state representatives in the consideration not only of screening but the total health needs of children. I would like to see the issue of early screening brought before the National Governors' Conference and the Regional Governors' Conferences. I feel strongly that too few state governors really understand the provisions of Title XIX and what might be available to appropriate state programs, especially now with bloc money obtainable which is not earmarked. I feel sure that if state executives and their staff members become more aware of all the things that can be done for children that are not presently being done, they will take more initiative in launching these comprehensive programs. I also feel they will realize that it is far more sensible and less costly to screen children adequately and early under a prevention and prompt remedial treatment concept, as opposed to caring for children on an institutional or long-term custodial care basis.

All of you who have taken part have been of great help to the President's Committee on Mental Retardation in further clarifying what needs to be done. We who serve on this body assure you that we shall use any influence

we might have in seeking to make your views and recommendations known--not only to the President as his appointees on a presidential committee, but to the Secretary of Health, Education and Welfare, all of the Cabinet officials, Members of Congress, and those specific Congressmen who sit on key committees capable of funding many of the recommended courses of action brought out in our session here.

The final point I would like to make is a re-statement of a long-standing conviction of the President's Committee on Mental Retardation, in our belief in the crucial need for more emphasis on public information. Great issues are usually resolved and major problems are usually dealt with only when the majority of the citizenry understand them and press for solutions. That is why it is urgent that the proceedings of this kind of significant Conference be made widely available to the public, written in layman's language, so that the general populace can recognize the importance of the subject matter we have been discussing.

We must always keep in mind that, although we speak of this country as being youth-oriented and sympathetic to the needs of children, we in America currently spend only one dollar in the area of child care for each nine dollars spent on the geriatric or older person. Dr. Tarjan spoke optimistically about the possibilities for change in this ratio of spending. I feel his optimism will be rewarded and justified when, and if, and only if every single person in America begins to recognize the urgent need for more comprehensive care, screening and treatment of children across the land. This Conference, it seems to me, can help us make a major start in this favorable direction.

On behalf of all of the members of the President's Committee on Mental Retardation, I want to express our sincere thanks for your interest, your cooperation, your intelligent participation and your eagerness to help us move ahead. We thank you, and we assure you we shall work hard in making sure there will be implementation. Thank you again for coming, and Godspeed in your journey home.

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